

# Examination of the *Rogers* Process for Youth in the Custody of the Massachusetts Department of Children and Families

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## **STUDY APPENDIX**

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This study examined the current process of obtaining informed consent for antipsychotic medications (i.e., medications for the treatment of certain severe behavioral and mental

health conditions) for youth in the custody of the Department of Children and Families (DCF) in the Commonwealth of Massachusetts. Since this protocol was adopted by DCF almost 25 years ago, there has been no evaluation of how the *Rogers* process is or is not achieving the intended purposes of providing safe, quality care, and oversight for youth in DCF custody.

The aim of this study was to examine the role of the *Rogers* process as a meaningful informed consent process for safe provision of antipsychotic medications for youth in DCF custody in Massachusetts.

## This appendix includes:

- A summary of *findings*, which discusses strengths, challenges, and recommendations identified by the following five stakeholder groups:
  - Child Welfare (DCF social workers, DCF staff, and DCF supervisors):
  - Consumers (parents, youth, and parent representatives);
  - Health Care Providers (clinical consultants, nurse practitioners, pediatricians, psychiatrists, and medical providers from residential settings);
  - Legal (attorneys, GALs, judges, and court clerks); and
  - Other State Agencies (DMH staff, DPH staff, and representatives from the Probate and Family court).
- A summary of *recommendations* across stakeholder groups.
- An overview of informed consent processes for the administration of psychotropic medications, as implemented by a select sample of states. These states include:
  - California:
  - Connecticut:
  - Illinois; and
  - Texas.
- A copy of the general *interview guide* used in this study.
- A copy of the *DCF regulation* stipulating the authorization process for the use of antipsychotic medications for youth in DCF custody
- *Additional resources* that may be useful for policy makers and child welfare advocates interested in informed consent for psychotropic medications.

## Summary of Findings by Stakeholder Group

One-on-one interviews and focus group discussions were the primary methods used to obtain information from a diverse group of stakeholders.

Data collection occurred in two phases. In the first phase, students from the Northeastern University School of Law (NUSL) Legal Skills in Social Context social justice program, in collaboration with the Tufts Research Team and the Office of the Child Advocate, conducted interviews with 109 representatives from five stakeholder groups. Ninety-three (85%) of these interviewees gave consent to participate in Phase 2 of this study. In the second phase, the Tufts Research Team, in collaboration with the Office of the Child Advocate, conducted an additional 21 interviews and 6 focus groups in an effort to increase equity of representation across all stakeholder groups. Data from these interviews and focus groups were combined with data from the Phase 1 respondents who consented to having data shared with the Tufts Research Team.

Using the three large domains of strengths, challenges, and recommendations as an initial framework, the research team independently reviewed a sample of interviews across stakeholder groups to identify an initial set of categories that might be used to organize responses that participants provided. These categories were revised using a process of coding and consensus commonly applied in qualitative research. A summary of the categories that were used to organize the input of participants is provided below.

## Overall Categories Used to Organize Input on the Rogers Process

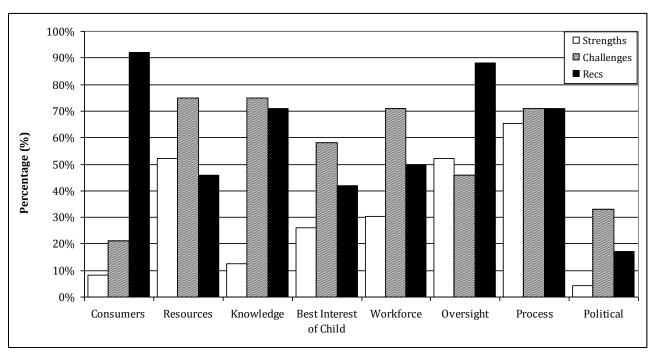
- **Best Interest of the Child** ("Best Interest of Child"): Ensuring that a child going through the *Rogers* process receives a thorough assessment, proper diagnosis, appropriate treatment approach, and that her/his opinions and wishes are represented to the greatest possible extent. Additionally, ensuring that a child receives the best possible care that maximizes her/his physical and emotional health in a timely, safe, and effective manner.
- **Consumer Engagement** ("Consumers"): The commitment and role that youth and parents have in the *Rogers* process, specifically around providing appropriate information and informed consent for treatment.
- **Political/Power Issues** ("Political"): The degree to which conflict of interest, trust among stakeholder groups, and questions of decision and authority affect the *Rogers* process.
- **Provider/Workforce Issues** ("Workforce"): Aspects of the *Rogers* process regarding staffing levels, quality of health care providers, standardization among health care providers, and the maintaining of professional standards.
- **Resources** ("Resources"): The time, money, and human capital invested by various stakeholders in different aspects of the *Rogers* process.
- **System Oversight** ("Oversight"): Processes that provide the capacity to regulate data, information, monitoring, and quality measures on either the individual client (child) or aggregate (system) level of the *Rogers* process.
- **System Process** ("Process"): Measures of the consistency, implementation, shared goals, collaboration, and alignment of skill sets to tasks throughout the *Rogers* process to ensure that the best, most effective and efficient system is in place to meet the needs of all involved youth and stakeholders.
- **Training/Knowledge Gaps** ("Knowledge"): Any lack in training or specific knowledge about psychosocial disorders, antipsychotic medications, and the *Rogers* process by various stakeholders.

#### **CHILD WELFARE**

Semi-structured interviews were conducted with 24 child welfare professionals (i.e., DCF social workers, DCF staff, and DCF supervisors). These professionals worked in various geographic locations throughout Massachusetts: 16% Central, 24% Metro Boston, 32% Northeast, 16% Southeast, and 16% Western. (*Note:* percentages do not total 100% because some professionals provided services in multiple regions.) Five of the 24 respondents were "boundary spanners," meaning they had experience working either with another state agency (e.g., DMH) or as a professional in another stakeholder group (e.g., mental health care provider).

Figure 1, below, provides an overview of the types of strengths, challenges, and recommendations identified by child welfare professionals. Respondents predominantly discussed challenges of the *Rogers* process and provided recommendations to improve the current process. Details on the most commonly noted strengths, challenges, and recommendations are presented in the following sections.

Figure 1. Strengths, Challenges, and Recommendations from Child Welfare Professionals across Domains (n=24)\*



\*Note: Recs = Recommendations.

#### **STRENGTHS**

The primary strengths identified by child welfare professionals can be categorized into four domains: (1) process, (2) resources, (3) oversight, and (4) workforce. Please see domains on page 6 of report for complete description.

#### • Process

Fifteen professionals (63%) identified strengths in the process that is currently in place to obtain a *Rogers* Order for a child in DCF custody. Of those who indicated the process as a strength, one third felt that having a GALsinvolved in gathering and synthesizing information provided to the courts about a child is an important safeguard for ensuring that judges have adequate background information on a child before rendering a decision about the appropriateness of antipsychotic medications for a child. Other respondents noted that simply having an oversight process (i.e., judicial review and approval) in place is important and valuable. Some participants commented on the strength of DCF and GALs working together, noting that the *Rogers* process works well when the various parties involved have access to appropriate information about the child.

#### Resources

Twelve professionals (50%) recognized resources as a strength of the *Rogers* process. Of those who identified this strength, one-third supported funding for training GALs to be important for the overall quality of any given *Rogers* case. Participants commented on the unique and important role of the GAL as "overseeing the whole story." Additionally, one respondent noted that GALs tend to be "more comfortable asking questions of everyone involved" in the *Rogers* process. Others expressed that in urgent or special circumstances (e.g., holidays), the process for obtaining an emergency order for the provision of antipsychotic medications was often timely. A few child welfare professionals also discussed the importance of having DCF attorneys and regional mental health specialists available for consultation and guidance. One respondent pointed out that once the preliminary steps are taken (i.e., paperwork has been completed, GAL has been appointed), the *Rogers* process functions relatively well.

#### • Oversight

Twelve participants (50%) identified oversight as a strength of the *Rogers* process. Of these individals, seven (58%) considered independent review of medication decisions by a third party (i.e., not affiliated with DCF) to be a strength. One participant noted, "It is good to bring it to another set of eyes who can look at it objectively...it keeps it policed..." Others identified GAL oversight as a strength, explaining that the GAL is the one person assigned to coordinating the steps in the *Rogers* process: "...I like that. There is someone looking over the process – and they have to because they have to report to the court." Respondents also felt that GAL oversight increases the likelihood that steps are taken to ensure the best interest of the child. Finally, a few professionals commented on the value of care coordination that can occur when a *Rogers* Order is needed. In order for the process to be successful, all stakeholders involved must be in communication with one another. As noted below in the challenges section, this does not always occur. However, when good communication is fostered, decisions about the best course of treatment for a child are easier to make.

#### • Other Strengths

Seven respondents (29%) noted strengths having to do with health care providers and workforce. Some identified the quality of attorneys and legal capacity, in certain regions of the Commonwealth, to hear *Rogers* cases as strengths: "...there are a lot of judges in Boston and this DCF office has a legal department that is quick to move on things like the *Rogers* process." Best interest of the child was cited by six respondents (25%). Specifically, professionals noted scrutiny in making medication decisions, pointing out that, due to the risks associated with antipsychotics, the decision to put a child on these medications should not be taken lightly: "It's a very serious thing to put a child on an antipsychotic...there are so many side effects. It's really a balancing act." These respondents also identified GAL involvement and training, and trauma-informed care as strengths.

## **CHALLENGES**

Important challenges encountered when a *Rogers* Order is required for a child in DCF custody were identified by 24 child welfare professionals. The most frequently recognized challenges fell into five domains: (1) resources, (2) knowledge, (3) workforce, (4) process, and (5) best interest of child. Below is an overview of the concerns raised in each of these primary areas.

#### Resources

The resource challenges under this domain included time, financial costs, and workforce or labor issues. Ten (40%) professionals pointed to the time it took for a *Rogers* Order to be approved. Concerns with the length of time needed to schedule court hearings were raised by 45% of those identifying resource concerns, voicing that scheduling often takes weeks to months. Many who work across regions also noted that this varies by region. With respect to workforce issues, 30% indicated that social workers spend a tremendous amount of time facilitating a *Rogers* Order through various channels. Of particular concern was the amount of time it takes to get a psychiatrist to complete the required affidavit stating the need for antipsychotic medications. Likewise, several child welfare participants noted that psychiatrists have expressed to them that the process is cumbersome; it simply takes too much of their time to complete an affidavit, meet with GALs and other stakeholders, and

potentially appear in court. This time is often not reimbursed by insurance companies and drains limited resources.

## • Knowledge

Fourteen (58%) professionals were concerned over the lack of training or knowledge about elements of the *Rogers* process, including protocol and procedure for obtaining a *Rogers* Order, information about psychotropic medications, and best treatment practices for youth in DCF custody. Only 13% of participants indicated that they had ever had any formal training on the *Rogers* process; of these, training was conducted only in the initial orientation to DCF. Nearly half of all participants learned about the *Rogers* process "on the job." Professionals also voiced that social workers are poorly equipped to deal with a *Rogers* Order in alignment with the best interest of a child in DCF custody. Topics raised for additional training include: risks and benefits of psychotropic medications, the *Rogers* process, and communication with psychiatrists and other health care providers to ensure that the treatment decisions are based on a comprehensive assessment.

GALs and psychiatrists were also identified as needing additional training. Child welfare professionals recommended training for both of these stakeholder groups on how the *Rogers* process works and what a *Rogers* Order entails. Additionally, child welfare professionals thought GALs should be trained on how to effectively communicate with health care providers and obtain a comprehensive child assessment.

#### Workforce

Many child welfare professionals (70%) recognized challenges regarding other professional stakeholders (i.e., psychiatrists, social workers, GALs, and judges) involved in the *Rogers* process. The variability in the quality and expertise of various stakeholders was of critical concern to child welfare professionals. Many were frustrated with the lack of consistency from case to case. Similar concerns were expressed about health care providers: some health care providers conduct a comprehensive assessment to determine the best course of treatment, while others were described as "prescription medication pumping machines." A few participants who worked in multiple courts noted great process variability depending on the jurisdiction. Professionals stated that some judges operate with a "rubber stamp," while others carefully review every case.

The lack of communication among stakeholders involved in a *Rogers* case was another concern of child welfare professionals. Participants acknowledged that lawyers, psychiatrists, and judges typically have large caseloads and a *Rogers* case requires considerable collaboration. However, there currently is no system for efficient and effective communication across stakeholder groups. Some professionals expressed that they often have to assemble all the different pieces of a *Rogers* Order to ensure the child receives proper treatment.

#### Process

Seventeen (70%) professionals identified challenges of the *Rogers* process itself. The most common concern was that the process for approving antipsychotic medication is too cumbersome, increasing stakeholder burden. Professionals thought some health care providers purposefully avoid the *Rogers* process due to the complexity of the process, prescribing a second-line treatment in lieu of an antipsychotic requiring a *Rogers* process. Others were concerned that a misaligned physician reimbursement mechanism limits the clinical attention a child receives, as well as the time health care providers spend on individual cases.

A smaller number of participants (21%) ardently asserted that the process of prescribing antipsychotic medications to youth in DCF custody should occur in a clinical setting rather than a courtroom. While they acknowledged the role of the judiciary as an independent authority, professionals felt that the burdens of the legal process greatly outweighed any benefits derived from judicial approval.

#### • Best Interest

Child welfare professionals expressed concerns about the impact on youth who are in psychiatric distress. Of greatest concern to participants is that the process often takes so long that youth are held in a higher level of placement (i.e., psychiatric hospital or residential program) for longer than is clinically appropriate. This often

occurs at two critical points in the placement of a youth in child welfare custody. First, when youth enter into custody with a previous antipsychotic medication prescription. For these youth, finding a placement is particularly challenging as many programs do not want to assume responsibility for obtaining a *Rogers* Order. The second critical juncture is when a youth is in transition; this occurs when youth in psychiatric distress are hospitalized for a short period of time and prescribed an antipsychotic medication. While often approved on an emergency basis, many programs will either not take the youth back into care or receive the youth as a new client until the *Rogers* Order is approved. This leads to "our children spending extraordinary amounts of time, unnecessarily, on a psychiatric unit because they can't be discharged to another level of care."

Another challenge, noted above, is that health care providers are not adequately reimbursed for the time and resources required to complete a *Rogers* Order. Several participants described experiences with psychiatrists who have told them that an antipsychotic medication is needed to treat psychiatric symptoms and "then suddenly change their minds about medications when they learn that a *Rogers* Order is required for the child to take an antipsychotic." This leaves many questioning the clinical judgment of health care providers and whether youth are receiving needed treatment, both in terms of whether an antipsychotic was even needed or if a child is receiving a second-line treatment because health care providers did not want to go through the *Rogers* process.

Another set of concerns was expressed about the quality of treatment that youth in custody receive. Several noted the use of medications as "quick fixes" for behaviors that are likely associated with histories of trauma, instability, and grief rather than biological imbalances. Some respondents felt the *Rogers* process is so time consuming that a full comprehensive psychological assessment is often not provided before determining the best course of treatment for a child in distress. Associated with this concern was that there is little to no systematic monitoring of medications once they are approved for use. Youth are kept on antipsychotic medications (and others) for long periods of time without careful review of whether or not they continue to be needed and effective. The *Rogers* process is an informed consent process, without an adequate monitoring and oversight process. However, the need for monitoring and oversight of antipsychotic and other psychotropic medications was clearly identified as a need among child welfare participants.

## RECOMMENDATIONS

The majority of child welfare professionals (70%) want to see either changes made to the current *Rogers* process, or the development of a substantially revised or new system to provide consent for antipsychotic medication use (termed "substantial" change below). Respondents wanted to ensure, first and foremost, that any improvements or changes result in a more efficient and effective decision-making and oversight system. While changes to the current process are desired, many respondents expressed concerns with the funding that would be required to make these changes. We discuss these by categories below.

## Recommendations for the Current Rogers Process:

#### Consumers

Nearly all participants (91%) provided recommendations on how to improve consumer (e.g., youth, biological and foster parents) engagement in the current *Rogers* process. Most reported that consumers are not adequately engaged in the decision-making process. When asked about whether consumers should be able to consent for antipsychotic medications, most participants (66%) indicated that consumers should have a voice in the decision-making process, but that ultimate consent should lie elsewhere. There was more disagreement amongst child welfare professionals with respect to the role that biological parents should play in decision-making; most noted that it would be difficult to have a uniform policy given that some parents are unable (i.e., both legally and cognitively) to participate in the decision-making process. Participants voiced the importance of birth parent involvement, particularly when the goal is reunification, so that parents understand the type and purpose of medications their child is taking.

With respect to youth being prescribed medications, one participant noted, "Kids are not puppets – they need to know what they are taking and why." The suggested age at which youth should become involved in the decision-

making process ranged from 12 to 16, with the majority of participants recommending engaging "older teens" so they can begin to learn to make choices about their own mental health treatment.

## • Oversight

Nearly all (88%) child welfare professionals recommended improving the oversight of antipsychotic medications for youth. Many recommended a more holistic approach to child-level monitoring, recording medications in addition to overall wellbeing, academic performance, peer relationships, and placement stability. A few noted that GALs may be the best individuals to provide this ongoing oversight and assessment, but this would require that they continue to participate and follow a child over a much longer period of time.

Child welfare professionals were largely in favor of extending the *Rogers* process to all psychotropic medications (i.e., rather than just antipsychotics), particularly if a child is prescribed multiple medications. Although participants thought this was in the best interest of the child, they expressed concerns that this would only increase the number of cases and time it takes to provide consent for these medications. Any expansion of oversight to other psychotropic medications would have to be accompanied by modifications in the efficiency and capacity of the *Rogers* process.

Finally, a few professionals, mostly supervisors, expressed the need for improvements in the DCF intake process to identify youth coming into the child welfare system who are already on psychotropic medications. They recommended including an "alert" function to prompt case workers to find out more about the medication a child is on and whether or not a *Rogers* process is required. Guidance on how to proceed with obtaining a *Rogers* Order would also be included in this process.

#### Process

The majority of participants (71%) recommended improvements to the actual process of providing informed consent for antipsychotic medications. As noted above, many child welfare professionals suggested substantial changes to the current *Rogers*. Specifically, they wanted decision-making to lie with clinicians, rather than with judges. Participants also stressed that the decision-making process should be timely and efficient. This emerged from concerns that youth are staying in hospitals and other restrictive care settings for extended periods of time while the courts gather the necessary information to process the *Rogers* Order. Two participants specifically noted that there should be a 48-hour turnaround for a decision unless there are extenuating circumstances. Participants also recognized that a quicker decision-making process would require better communication among DCF, psychiatrists, GALs, attorneys, youth, and guardians.

### • Knowledge

Ensuring that all stakeholders have proper training and knowledge was recommended by 70% of child welfare professionals. Participants identified a number of areas where training is needed, including: (1) the *Rogers* process itself, e.g., what it is, why we use it, what medications require court approval, etc.; (42%), (2) specific knowledge on psychotropic medications (29%), and (3) communication strategies to ensure sound medical decision-making with health care providers (20%). Social workers were identified as a group in particular need of additional training in these areas. A number of participants also noted that health care providers need specific training on the *Rogers* process. In addition, professionals recognized the importance of GALs in the current *Rogers* process and the relationship between the quality of the GALs and process outcomes.

## • Workforce

One of the challenges that several participants identified is our current mental health care system. Specifically, participants noted that psychiatrists are increasingly faced with less reimbursable time with a patient to gather comprehensive and historical information about a person to inform an opinion about an underlying condition. Treatment recommendations should stem from this informed perspective. However, participants noted that one of the biggest faults of our current process is that psychiatrists often do not have all the information they need to understand the youth's behavior in the context of his or her life. Developing better channels of communication among DCF social workers, psychiatrists, and consumers is an important recommendation for improving the

*Rogers* process, or any other process that may be considered in Massachusetts. Another recommendation offered by participants is to improve the standardization of psychiatric practice. Several participants noted that not all psychiatrists view or treat antipsychotics as "extraordinary treatment" and this impacts their willingness to follow through with the *Rogers* process in a timely manner.

## **Recommendations for Substantial Change:**

- Slightly less than half (42%) of all child welfare respondents recommended substantial reform to the *Rogers* process. Most of these respondents (60%) recommended creating an independent panel, comprised primarily of medical and social work professionals, to review and consent for psychotropic medication treatment. The models employed in Illinois and Connecticut were specifically noted as ideal by several participants (see state summaries in this *Appendix*). Of those who recommended substantial reform, 30% of participants recommended the creation of a review panel, seated within DCF, that would be responsible for asking questions of health care providers and, ultimately, for making decisions about the medication treatments.
- Whether located within DCF or within the community (e.g., university-based panel), child welfare respondents noted the need for trained medical professionals with a solid understanding of issues that confront youth in the child welfare system, and a system that is capable of identifying "red flags" or triggers for additional review and oversight. Many participants expressed concerns that youth are being over medicated, or are not monitored carefully and efficiently to ensure that they are on the lowest possible dosage of a medication.
- One individual expressed an interest in including consumer voice through an independent panel to ensure that the real-life impact of medication decisions is considered.

#### HEALTH CARE PROVIDERS

Semi-structured interviews were conducted with 31 health care providers (i.e., child and adolescent psychiatrists, pediatricians, nurse practitioners, and medical providers in residential settings). These health care providers were geographically dispersed across the state: 16% Central, 58% Metro Boston, 16% Northeast, 3% Southeast, and 16% Western (*Note:* These percentages do not total 100% because some practitioners provide care in multiple regions of the state). Relative to the number of challenges identified in the interviews, health care providers recognized fewer strengths with the current *Rogers* process. The vast majority of health care providers (87%) recommended some revision to the *Rogers* process; 39% endorsed a total revamping of the policy. Approximately 13% felt the process should stay the same with only minimal changes. A more detailed account of the strengths and challenges identified by health care providers follows, as well as their suggested recommendations to improve the process.

In addition, a focus group was conducted with three health care providers who provide care at residential or inpatient units. Of note, focus group respondents' comments are not included in proportions presented in the figure and text below, as responses are not independent of the group process and, as such, cannot be summarized as counts.

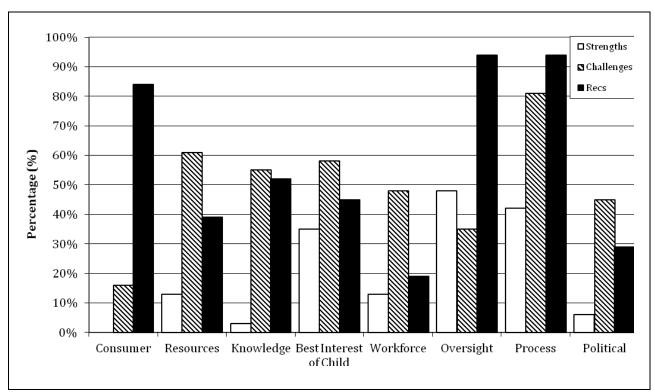


Figure 2. Strengths, Challenges, and Recommendations from Health Care Providers across Domains (n=31)\*

\*Note: Recs = Recommendations. Proportions displayed here do not include the three health care providers who participated in the focus group.

#### **STRENGTHS**

The majority of the strengths identified by health care providers fell into three domains: (1) oversight, (2) process, and (3) best interest of child.

#### • Oversight

Fifteen (48%) health care providers felt that oversight is a strength of the current *Rogers* process. Of those indicating this strength, all 15 felt that there should be a process of oversight that emulates what parental figures would typically provide for their children. One health care provider stated, "If those kids don't have parents to look out for them because they're in state custody, there should be a process for someone to provide oversight." This finding indicates that the health and safety of youth in DCF custody is a priority for health care providers.

#### Process

Thirteen (42%) health care providers felt that the process of obtaining a *Rogers* Order is also a strength. Of those who identified this strength, 57% specified that the *Rogers* process works under conditional circumstances. For example, health care providers said, "When it's done correctly, I think it works," and "Often in order to be successful it is really important to have a collaborative working relationship with everyone involved in the process". In contrast, 21% of those who identified process as a strength felt that the *Rogers* process works rather consistently. Other strengths within this domain included intent of the process (21%) and the deterrence of hasty prescribing practices (14%).

#### • Best Interest of Child

Eleven (35%) health care providers acknowledged that the *Rogers* process works in the best interest of the child. Similar to the themes identified within the process domain, health care providers endorsed the slowing of prescribing practices (55%), the good intentions behind the process (18%), and the overarching purpose of protecting youth (27%). A small portion of health care providers (18%) from this domain voiced that the *Rogers* process is flexible because youth can be administered medications in emergency situations.

## • Other Strengths

Lastly, a small proportion of health care providers identified strengths in the following domains: resources (13%), workforce (13%), political (6%), and knowledge (3%). Within these domains health care providers highlighted the responsiveness and training of GALs, the time and effort to complete a *Rogers* request, and collaboration among stakeholders as positive aspects of the process. Of note, no health care providers identified consumer engagement as a strength.

## **CHALLENGES**

The majority of challenges identified by health care providers fell into the following domains: (1) process, (2) resources, (3) best interest of child, and (4) knowledge.

These same challenges were also identified by focus group participants (not included in counts below). In particular, health care providers in residential and inpatient facilities focused on process issues, describing dealing with acutely ill youth for whom medications could be essential and yet facing barriers to using medications, resulting in injury to either the patient or health care providers.

#### • Process

Twenty-five (81%) health care providers identified challenges with the *Rogers* process itself. Of those recognizing these challenges, over half (52%) found the process to be ineffective. For example, when asked how the *Rogers* process is working, a health care provider simply stated "[It's] not working." Specific issues within the process that were identified as problematic include: burdensome process (44%), lack of collaboration among stakeholders (40%), inconsistencies with the process (32%), and inefficiencies (e.g., among health care health care providers there is sentiment that there could be a "quicker and easier way" [20%]).

## • Resources

Nineteen (61%) health care providers recognized the constraint, misuse, and misappropriation of resources within the *Rogers* process. Three-quarters (74%) of those voicing concern over resources identified time as the scarcest resource. The many hours needed to complete affidavits and lags in the process were frequently acknowledged for decreasing efficiency and timeliness. Over half (53%) identifying resource constraints stated how burdensome the process can be, "...the Roger process was a 'resource suck' in terms of what judges, doctors, GALs, and DCF staff could be doing to help youth if their resources weren't tied up in the process..." Approximately 21% within this domain identified a misaligned reimbursement system as a resource constraint; for example, time outside of direct patient contact is not billable. Additionally, incentives currently favor quantity of cases over quality of reports resulting in overloaded GALs and DCF staff, which impact the youth's quality of

care. Of these health care providers, only 11% recognized state fiscal constraints as a major challenge to the process.

#### • Best Interest of Child

Hindrances to youth receiving care or services in their best interest are recognized by 18 (58%) health care providers. Of those, the majority (61%) acknowledged challenges to the quality of care youth receive, including instances where the *Rogers* process deters the quality of care to a child for a variety of reasons. Additionally, delays in the timeliness of care were noted by half of health care providers (50%). Half (50%) also endorsed the *Rogers* process as a barrier to treatment. Approximately a quarter (28%) thought that health care providers altered treatment choices solely to avoid the *Rogers* process. Another theme voiced by health care providers within this domain was conflict over the best interest of the child, typically arising from differing perspectives on the "best interest." A health care provider noting this conflict stated, "The law forces people into bad process[es] in order to meet the needs of the child."

#### Knowledge

Deficiencies in training and knowledge on specific topics across stakeholder groups were expressed by 17 (55%) health care providers. Of those noting this challenge, 53% identified explicit knowledge of antipsychotic medications (i.e., new medications, dosages, and side effects) as a knowledge gap. Further, participants (18%) expressed a lack of information on the *Rogers* process among all stakeholders. In terms of different stakeholder groups, a majority of health care providers (59%) voiced that judges do not have adequate knowledge or training. One health care provider stated, "The judge is making the call and the judge is clearly not qualified to make the call." Subsequently, 35% of health care providers within this domain expressed a lack of sufficient training and knowledge among social workers. Twenty-four percent and 18% of these participants also suggested the same of GALs and attorneys, respectively. A call for routine training on both the medications and the *Rogers* process was made by 6% of these health care providers.

#### • Other Challenges

Several other challenges were identified by health care providers but to a lesser extent. Specifically, these participants recognized challenges within the following domains: workforce (48%), political (45%), oversight (35%), and consumers (16%). Major challenges among these domains include a lack of professional standards, tensions across stakeholders, exclusion of other psychotropic medications, and lack of consumer engagement.

#### RECOMMENDATIONS

Recommendations are presented in two overarching categories: (1) recommendations for the current *Rogers* process and (2) recommendations for substantial change.

## Recommendations for the Current Rogers Process:

Recommendations for improving the current *Rogers* process fell into four domains: (1) oversight, (2) process, (3) consumers, and (4) knowledge.

#### • Oversight

Twenty-nine (94%) health care providers voiced that improvements to the *Rogers* process can be made by enhancing oversight. Of those participants, 48% suggested that stakeholders ensure that the appropriate system is in place. Specifically, health care providers felt that there needs to be a "flexibly responsive system to mimic the role of a responsive parent or caretaker...". Among those offering oversight recommendations, there was a desire for increased child-level (41%) and population-level monitoring (10%). Additionally, approximately 21% suggested enhanced monitoring to ensure quality care for youth in DCF custody. To further promote quality of care, health care providers recommended broadening oversight to all psychotropic medications (45%) and polypharmacy use (14%). However, of those suggesting oversight recommendations, two participants (7%) did not want to add additional medications to the *Rogers* process. Finally, to ensure a good system, health care providers with oversight recommendations suggested regular evaluation of the *Rogers* process itself (10%), a review of associated costs (7%), and a review of outcomes (14%) to ensure a good system.

#### • Process

Recommendations for improving the consent process for antipsychotic medications were indicated by 29 (94%) health care providers. Of those, 59% expressed improving the process itself, 35% wanted increased efficiency, and 14% recommended a simplified process. These system-level concerns arose from inefficient court involvement and a general lack of standardization that, if remedied, could potentially translate into better use of time and effort for those involved. Increased collaboration was recommended by half (48%) of these participants. Channels for improved communication were said to improve both the process and youth outcomes. A participant stated the process should, "...align everyone's responsibilities to the patient based on the strengths of their training and discipline, and collaborate as opposed to overlap, we will be creating a process that is probably more effective and hopefully more efficient." This call for increased efficiency was echoed by the 21% of participants recommending shared goals across the process. These common objectives included improved youth outcomes, safety, efficiency, and consistency throughout the *Rogers* process. Shared goals included achieving agreement among foster parents, health care providers, and social workers, as well as health care providers and judges mutually representing the best interest of the child.

#### Consumers

Twenty-six (84%) health care providers recommended improving consumer engagement. Of the health care providers commenting on consumer engagement, the majority (73%) expressed that youth should have higher involvement in the process. The lack of youth involvement in diagnosis and treatment decisions was commonly voiced, for example, "I think as kids get older, they will have more say in what's going on in their lives. There is certainly a developmental trajectory of increasing capacity approaching the age of majority. You absolutely want to hear what the kid's preferences are." A call to engage developmentally mature youth was echoed by some (42%) participants; however, it was suggested that determination of this maturity is best addressed on a case-by-case basis.

Over half (54%) of participants wanted greater foster parent involvement. Foster parents are often responsible for administering medication so increasing their knowledge, opinions, and involvement could lead to improved treatment adherence and outcomes. Some health care providers (8%) voiced conditional involvement for foster parents, favoring longer-term, well-established placements to become involved if a stable environment has been demonstrated. Approximately a quarter (27%) of participants within this domain supported an increase in biological parent involvement. Most agreed that biological parents should remain informed on any diagnosis and/or treatment decisions. Conditional biological parent involvement was endorsed by 23% of health care providers. Biological parents were also identified as an important influence in their child's life; a health care provider stated, "The birth parents' opinions on medication can influence how the child feels about the medication. Many of the youth will feel they are betraying their parents if they are taking medicine their parent doesn't want them to." Depending on the level of influence and involvement in youth's life, biological parents are an important consumer group throughout the *Rogers* process.

## • Knowledge

Sixteen (52%) health care providers commented on improving the *Rogers* process through increased training and knowledge. Increased training and knowledge was recommended for judges (38%), lawyers (25%), GALs (25%), and health care providers (25%). One health care provider noted, "Training would be really helpful, and it would be particularly helpful to have a good pharmacological training, that's a big piece of it, knowing how these different medications interact and also how the medications affect different things." In terms of knowledge gaps on specific topics, half (50%) of health care providers within this domain suggested education on mental health disorders and corresponding medications, a third (31%) recommended information on the *Rogers* process, and nearly a fifth (19%) wanted regular training sessions.

#### Other Recommendations

Lastly, other recommendations fell into the following domains: best interest of child (42%), resources (39%), political (29%), and workforce (19%). Specifically, improved quality of care, a streamlined process, enhanced collaboration, and increased quality of stakeholder services were recommended as improvements to the current process.

## **Recommendations for Substantial Change:**

Twenty-four (77%) health care providers suggested creating an entirely new process, ultimately substantially reforming the informed consent process. Specifically, health care providers proposed granting decision-making authority to different stakeholder groups (i.e., DCF and medical personnel). Participants also suggested the inclusion of certain types of medications within this oversight process and the degree to which youth, biological parents, and foster parents should be involved in the process. These recommendations are discussed in more detail below.

## • Process

Sixteen (67%) health care providers suggested four additional review processes: (1) review panel of peers (69%), (2) university based panel (46%), (3) peer review conducted via telephone (18%), and (4) psychiatry consultation (9%). Eight (26%) health care providers suggested that DCF should be the body to provide informed consent for youth in DCF custody. Specifically, participants offering reform recommendations suggested that: DCF workers should provide consent (38%), DCF supervisors should provide consent when DCF workers do not feel competent (38%), DCF should assemble a specialized team within their department to provide consent (37%), DCF should appoint specialized medical guardians to provide consent (13%), and DCF should hire its own in-house child and adolescent psychiatrist (13%).

When asked what the oversight would look like in an ideal world, 17 (52%) health care providers recommended various levels of judicial involvement. Specifically, 16 (94%) of these respondents felt that the judiciary should be detached from the process of providing medication oversight. One respondent commented, "It's a little concerning. There's a little bit of absurdity, judges making medical decisions is a little like doctors making criminal decisions. In a perfect world the court wouldn't be involved..." Finally, one health care provider (6%) felt that the courts should remain involved, but only in terms of providing oversight to a medical guardian, ensuring their investment in the child's well-being.

#### Oversight

Six health care providers (19%) were concerned that the *Rogers* process only provides oversight of antipsychotic medications and that it lacks additional monitoring for youth who may be prescribed multiple psychotropic medications. Because of these concerns, 83% of these respondents suggested expanding oversight to all psychotropic medications, and 50% suggested oversight for polypharmacy use.

#### Consumers

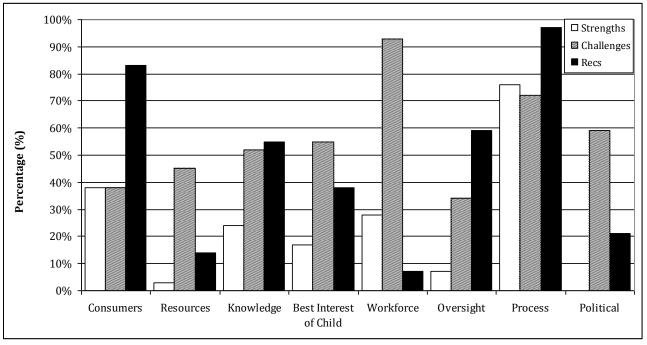
Finally, among those who supported an alternative mechanism for antipsychotic medication oversight, many felt that consumer engagement is an important aspect of quality care. Specifically, 12 (39%) health care providers expressed that the child's voice is important in treatment planning. Despite this, health care providers did not feel comfortable giving youth decisional authority, as many of the youth they work with do not have the mental capacity to make these final judgments (e.g., developmentally too young to understand the implications of medication or are in acute distress). Six participants (25%) also felt that having the biological and foster parents' voices are important; however, these are conditional on their level of involvement with the child. Only one health care provider (8%) felt that the foster parents should not be involved in the process because they have no legal rights.

#### **LEGAL**

## **Attorneys and GALS**

Semi-structured interviews were conducted with 29 attorneys, DCF attorneys, and GALs. The attorneys and GALs were geographically dispersed across the state: 24% Central, 52% Metro Boston, 24% Northeast, 21% Southeast, and 14% Western (*Note*: Percentages do not total 100% because some attorneys and GALs practice in multiple regions of the state). Relative to the number of challenges identified in the interviews, fewer strengths of the *Rogers* process were recognized by attorneys and GALs. However, 43% recommended minimal revisions to the *Rogers* process, 33% recommended moderate revisions, and 23% endorsed substantially reforming the process. A more detailed account of the strengths and challenges identified by this stakeholder group follows, as well as suggested recommendations to improve the process.

Figure 3. Strengths, Challenges, and Recommendations from Attorneys and GALs across Domains (n=29)\*



\*Note: Recs = Recommendations.

#### **STRENGTHS**

The majority of strengths identified by attorneys and GALs fell into three domains: (1) process, (2) consumers, and (3) workforce. It should be noted that these responses directly contradict those heard from consumers. We would recommend that future efforts to capture consumer perspectives be conducted prospectively immediately following a *Rogers* hearing.

#### • Process

Twenty-two (76%) attorneys and GALs cited the process used to provide informed consent for administration of psychotropic medications to youth in the welfare system as a strength. Of those indicating the process as a strength, 36% indicated that the process ensures stakeholder accountability and oversight. Twenty-seven percent of those who recognized the process as a strength felt that the process ultimately ensures the correct medication for youth. For example, one respondent said, "It forces doctors to really think about medication they're giving kids." About a fifth (18%) of attorneys and GALs who commented on this domain as a strength, felt that the *Rogers* process leads to an objective review of cases. Other strengths that were identified within this domain, but to a lesser degree, included: efficient and timely process, ensures stakeholder communication, ensures consumer engagement, and ensures continued review.

#### Consumers

Eleven (38%) respondents identified consumer engagement as a strength of the current process. Of those, 64% found youth involvement to be a particularly strong component of the *Rogers* process. Although none of the stakeholders indicated that youth should function as final decision-makers, each agreed that they had a central role in informing the stakeholders of their experience with psychotropic medications. Stakeholders highlighted the manner in which judges engage youth in hearing about their experiences with specific medications as examples of youth engagement. One participant recalled, "I represented one girl who was very articulate about the whole thing - specifically that she didn't like someone else forcing her to put these things in her body... she wanted the opportunity to tell the judge herself about her dislike for taking the medications... I presented her concerns to the judge, and mentioned that she would like the opportunity to speak with him for herself... the judge actually ended up going to her, so they could talk. I was able to get her off of some of her medications."

Finally, attorneys and GALs who cited consumer engagement as a strength indicated that the involvement of foster (36%) and biological parents (27%) was a strength to the process. Many of these stakeholders indicated that judges are particularly interested in "hearing from the people with whom the youth spend most of their time."

## • Workforce

Eight (28%) attorneys and GALs endorsed workforce as a strength of the current process. The majority of these eight respondents (88%) were impressed with the quality of the workforce, within the court and legal sector, as well as in the medical field. Thirty-eight percent of those indicating workforce as a strength to the *Rogers* process felt that stakeholders, including the GALs, judges, attorneys, and health care providers, offer attention to detail, which is an asset to the process. A quarter (25%) of respondents felt that professional knowledge of the process and psychopharmacology are strengths. Finally, other noted strengths related to stakeholders' commitment to maintain high standards of their profession (13%) and respect for the process (13%). One informant said, "Overall the process works well because the people I work with do a good job. The reports are detailed, and they are for the most part very attentive, so I feel that I can provide good quality recommendations."

#### Other Strengths

Lastly, a small proportion of attorneys and GALs identified strengths in the following domains: knowledge (24%), best interest of child (17%), oversight (7%), and resources (3%). Within these domains attorneys and GALs highlighted availability of training, protecting vulnerable youth, ensuring quality care, and appropriate use of resources as strengths of the *Rogers* process. Of note, no attorneys and GALs identified strengths within the political domain.

## **CHALLENGES**

Attorneys and GALS were highly concerned about maintaining the integrity of the current process. These stakeholders were concerned that challenges in four specific domains were a threat to maintaining the fidelity of the process. These domains included: (1) workforce, (2) process, (3) political, and (4) best interest of child.

#### Workforce

Twenty-seven (93%) attorneys and GALs expressed concerns about health care provider and workforce issues. These respondents were concerned with two major issues: (1) inconsistencies in health care provider practice and (2) limitations in workforce capacity. Of those, an overwhelming majority (89%) acknowledged concerns with a lack of consistency in practices throughout the medical and legal sectors. Respondents cited differences in the quality of health care providers, raising concerns about health care providers' adherence to their own medical standards with respect to quality of care. Other attorneys and GALs expressed concerns about a lack of consistency within the legal sector. For example, some reported that there are differences in the quality of GALs' comprehensive reports. One participant said, "Judges have evolved their own little rules, so there could be some clarification. One judge only wants a *Rogers* affidavit to be signed by doctors, not by prescribing nurses." A small percentage of stakeholders expressed concerns about persistent shortfalls in the current workforce capacity as a

threat to maintaining the current process. This concern was most evident with respect to the medical workforce. Most were concerned with shortfalls in the number of clinicians able to provide mental and behavioral health services. One respondent stated, "There have been cases where I have represented youth taking an antipsychotic medication, but the child was taken off the medication when the *Rogers* Order was required because there was no available psychiatrist to write the affidavit."

#### Process

Twenty-one (72%) attorneys and GALs were concerned with the process by which informed consent is provided for the administration of antipsychotic medications. Of those, 52% of attorneys and GALs indicated concerns with lack of standardization throughout the process. For example, one stakeholder said, "Depending on the judge, you will get an order anywhere from six months to a year." Another stakeholder indicated that the "biggest frustration is the doctors and their unwillingness to comply with the *Rogers* process, the affidavit is 24 pages long, so they don't end up being very useful... it was created by courts, CPCS, and DCF all in conjunction, and was supposed to be used across the state to help standardize the process." A quarter (23%) of respondents commented on inefficiencies in the process due to a lack of communication among stakeholders and a lack of coordination of services. One respondent said, "A better coordinated effort is necessary... in the probate court their idea of making a more efficient system is to make it a paper chase." Another attorney stated, "Sometimes, unless I actively monitor what is going on, I don't know what is happening with the medication. If the doctor wants to change the medications, only sometimes will they notify me."

#### Political

Seventeen (59%) attorneys and GALs expressed concerns about power issues within the current process. Of those, eight (47%) highlighted concerns regarding an imbalance of power. Namely, power imbalances were noted between mental health providers and GALs (24%), as well as between mental health providers and social workers (12%). One GAL stated, "I don't feel comfortable questioning a good psychiatrist." In addition to concerns around power imbalances, respondents expressed concern with a lack of cooperation among stakeholders. Specifically, most noteworthy is the lack of cooperation between providers and GALs (29%), as well as between providers and judges (18%). An unwillingness to communicate and provide timely affidavits to GALs was the mostly frequently cited concern. One stakeholder said, "A court order to the doctors would help. I get such a feeling that the doctors believe the court is interfering. Why not give them a copy of the *Rogers* section that says the court is your client. You convince the court to medicate, or you can't... they need to be summoned in on a regular basis." Finally, some (24%) informants expressed concerns with questioning professional decisions, which is innate to the current process. Such questioning can create conflicts and ill-formed decision making. One respondent said, "A collaborative approach is a great idea, but doctors, lawyers, and judges speak in two different languages and anyone resents having someone encroach on their expertise... would judges want doctors telling them how to make judicial decisions?"

#### • Best Interest of Child

Sixteen (55%) attorneys and GALs felt that the best interest of the child is not being met. Of those who expressed concern regarding the best interest of the child, 13 (81%) respondents expressed concerns that a holistic approach to care is not occurring. One respondent stated, "There is a tendency to use medication as a chemical restraint. It is difficult for agencies; it might be easier to manage kids by putting them on medications than to provide them with services." Another respondent said, "Doctors try to get a huge range of dosages approved because they don't want to have to write the affidavit to get another dose approved, but the dosages they are asking for are huge." A third respondent expressed concerns that some youth do not need these medications at all, stating, "Children are not receiving the medication because clinicians do not want to come to court... this begs the question of whether the child ever needed the medication."

Other issues within the best interest of the child domain that were raised, but to a lesser extent, related to the timeliness of care (6%), lack of objective review (6%), and lack of appropriate treatment (6%).

## • Other Challenges

Several other challenges were identified by attorneys and GALs, but to a lesser extent. Specifically, these stakeholders recognized challenges within the domains of: knowledge (52%), resources (45%), consumers (38%), and oversight (34%). Major challenges recognized within these domains included: lack of a formal training process, time consuming nature of the process, inconsistent consumer engagement, and inconsistent and inadequate level of monitoring.

## **RECOMMENDATIONS**

Recommendations are broken down into two overarching categories: (1) recommendations for the current *Rogers* process and (2) recommendations for substantial change.

## Recommendations for the Current Rogers Process:

Many of the participants recommended making minor changes to the current process. Areas where there were the most suggestions for improvements included: (1) process, (2) consumers, and (3) oversight.

#### Process

Twenty-eight (97%) respondents identified recommendations for improving the informed consent process. Specifically, of those providing comments on the process, many were interested in additional standardization of the *Rogers* process to improve its efficiency and uniformity across the Juvenile Court system. Several stakeholders (14%) recommended developing a comprehensive, but streamlined, affidavit to be used across the Commonwealth. Others recommended revising the current list of medications governed by the *Rogers* process to include a review of medications with larger side effect profiles as well as review of situations in which more than one psychotropic medication is used at the same time. Some participants recommended establishing clear guidelines for the frequency of review of *Rogers* cases (11%) as well as clarifying the roles of participating stakeholders during the information gathering and court procedures (4%).

#### Consumers

Twenty-four (83%) participants endorsed the need for involving youth, biological, and foster parents in the *Rogers* process. Of those, three quarters (75%) agreed that youth should have a voice in the *Rogers* process, with most (54%) indicating that youth should help to inform the process, and some (8%) recommending that youth have decision-making authority. However, 46% of attorneys and GALs who indicated a need for greater youth involvement recommended that their involvement be conditional. For example, one participant stated, "Whatever the age of the child, their opinion needs to be told to the board and the older they get, the more their opinion has to count." Over half (54%) of participants agreed that the voice of foster parents should also be considered in this process, and 71% felt that biological parents should be considered as well. Few respondents (4%) supported giving foster and biological parents decision-making authority in providing informed consent for the administration of psychotropic medication to youth.

## • Oversight

Seventeen (59%) attorneys and GALs recommended improving the oversight of psychotropic medications for youth in DCF custody. Of those 76% recommended making changes to the *Rogers* process, which would allow for improvements in the ability of the process to monitor quality of care. Areas in need of greater monitoring included child well-being (29%), the timeliness of the process (18%), and assuring that youth in DCF custody receive the appropriate treatment, which may include alternative, more holistic treatments (12%). As was mentioned in the recommendation for process, many (41%) stakeholders endorsed providing oversight for a larger number of medications administered to youth in DCF custody.

## • Other Recommendations

Attorneys and GALs also made recommendations in the following domains: knowledge (55%), best interest of the child (38%), political (21%), resources (14%), and workforce (7%). Specifically, formal training, ensuring quality care, increased stakeholder participation, increased workforce and general resources, and aligning responsibilities with workforce expertise were recommended as improvements to the current process

## **Recommendations for Substantial Change:**

Slightly less than one quarter (23%) of the attorneys and GALs recommended substantially reforming the current process of providing informed consent for the administration of antipsychotic medications. A third of these participants (33%) recommended a process that employs an independent panel comprised primarily of medical or university professionals, to review and consent for psychotropic medication treatment. Fewer (17%) of those who recommended reform suggest that (1) nurse practitioners could serve as monitors, (2) DCF social workers should provide consent, (3) the judicial system should be removed from the review process (e.g., one participant said, "Why do we assume that lawyers are able to do this work? That's the problem and challenge. Frankly, medical and health professional[s] are better equipped to do this job."), and (4) the courts should employ their own specialized doctor(s) to provide expertise.

#### **LEGAL**

## **Judges**

Semi-structured interviews were conducted with 11 judges in the Juvenile Court. These judges were geographically dispersed across the state: 18% Central, 36% Metro Boston, 36% Northeast, 17% Southeast, and 13% Western (*Note*: These percentages may not total 100% because some judges sit in multiple regions of the state). Overall, judges were more likely to identify challenges in the current *Rogers* process than its strengths. The majority of judges noted that the current process (64%) and oversight (55%) were strengths of the *Rogers* process. Additionally, the vast majority of judges (82%) recommended that the Juvenile Court continue to authorize the use of antipsychotic medications among youth in DCF custody. The majority of judges (64%) recommended revision to the *Rogers* process, whether moderate or substantial, and approximately 36% recommended minor, if any, changes. A more detailed account of the strengths and challenges identified by judges follows, as well as suggested recommendations to improve the process.

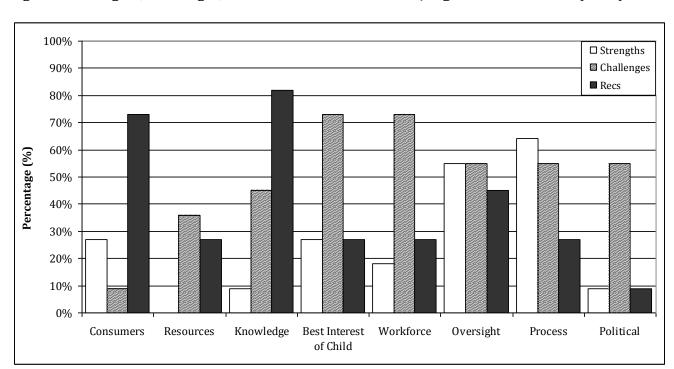


Figure 4. Strengths, Challenges, and Recommendations from Judges across Domains (n=11)\*

\*Note: Recs = Recommendations.

#### **STRENGTHS**

The majority of the strengths identified by judges fell into four domains: (1) process, (2) oversight, (3) best interest of child, and (4) consumers.

#### Process

Seven (64%) judges felt that the process of obtaining a *Rogers* Order is a strength of the *Rogers* process. Of those indicating this strength, four suggested that the *Rogers* process works under specific circumstances. Specifically, one judge said, "When everyone is really well trained and perform their roles well, you can get a lot of information...in these cases, there are technically even more people looking at the situation and asking questions than would be for a child who is still living with her parents." Another judge stated, "...if I'm given all the information I need I think I could make a good decision." Two judges indicated that the process generally works well. One judge identified access to two court clinicians (both a psychiatrist and psychologist) as a "blessing"; these court clinicians are available to provide consultation about mental health concerns, including those raised

during the *Rogers* process. One judge noted the process prevented a "rubber stamp" approach to the authorization of antipsychotic use among youth in DCF custody.

## • Oversight

Six (55%) judges felt that oversight is a strength of the current process. Of those who identified oversight as a strength, four identified the benefit of judicial oversight, which provides a "neutral" or "objective" third-party review. One judge said, "I think the judicial oversight is a critical piece. This ensures that there is neutral oversight in the administration process, to make sure these medications are not used for other than a medical need, for example to control behavior." Two judges who identified oversight as a strength felt that the *Rogers* process offers ongoing monitoring, "I think the system works because we're watching them and monitoring (medications)." Two judges also indicated that judges provide a safeguard and necessary level of scrutiny unavailable to other stakeholders, including DCF. One judge noted the value of the *Rogers* process to provide "checks and balances," and the value of providing oversight to antipsychotics, alone, as they are an easy trigger for the *Rogers* process.

## • Best Interest of Child

Three (27%) judges acknowledged that the *Rogers* process is working in the best interest of the child. Similar to the themes identified within oversight, two (66%) judges noted that the analysis necessary to issue the substituted judgment decision requires the judge to evaluate myriad aspects of the case (e.g., risks and benefits of treatment options, impact on family, youth consent, etc.). Another judge (33%) indicated that the judge is "the last gate of protection" for these youth.

#### Consumers

Three (27%) judges felt a strength of the current *Rogers* process is consumer engagement. All three indicated the involvement of youth in the *Rogers* process as a strength. One judge said, "As long as I am reasonably sure that they won't put themselves at risk, I will often defer to their judgment, even for 15 or 16 years olds, if they present well and seem capable of taking on that decision." Another judge felt that the involvement of biological parents, if parental rights were not terminated, is a strength of the *Rogers* process.

#### Other Strengths

Lastly, a small proportion of judges identified strengths in the following domains: workforce (18%), political (9%), and knowledge (9%). Within these domains, judges highlighted the responsiveness and training of GALs, the minimal time and effort to complete a *Rogers* request, and collaboration among stakeholders as positive aspects of the process. Of note, no judges identified resources as a strength.

#### **CHALLENGES**

The majority of challenges identified by judges fell into the following domains: (1) best interest of the child, (2) workforce, (3) process, (4) oversight, and (5) political.

#### • Best Interest of Child

Eight (73%) judges identified challenges with the *Rogers* process in ensuring the best interest of the child. Four of these eight (50%) judges indicated that the mental health care delivery system is too focused on the quick fix; the *Rogers* process, alone, is unable to remedy this. One judge said, "We're looking for quick fixes throughout the system...we ought to be more careful. We've created [the *Rogers* process] where 90% of the cases rubber stamp what the health care provider has recommended, rather than really questioning whether this is the best interest. There is no context." Two (25%) judges indicated concern around the use of antipsychotics to control behavior, rather than treat psychosis, explicitly. Two (25%) judges indicated that the multiple transitions for youth in DCF custody may increase the amount of medication prescribed to the youth. One (13%) judge indicated concern around health care providers not attending to the side effects of medication; another commented on the injustice for youth in DCF custody when psychotropic medication oversight is ceded to DCF alone.

#### Workforce

Eight (73%) judges recognized variation in the quality of the workforce involved in the *Rogers* process as a constraint to the current process. Of those who identified challenges in the quality of the workforce, four (50%) judges indicated the variation in the quality of GALs as a particular challenge. One judge said, "I rely heavily on the GALs, because I cannot go out to visit the child. The GALs genuinely want to help, but a lot of the time they don't know what questions to ask. Once the child is stabilized, what should the treatment be? What is the child's life like? The GALs are always getting battered up by my questions." Three (38%) judges indicated variation among health care providers, both clinically and administratively, as a challenge to the current *Rogers* process. One judge said, "I think there are not enough child psychiatrists to start with. And second, there is a very small pool of people who take MassHealth and so they're overworked. They see a kid once a month for 10 minutes. I think the psychiatric care for youth in [the] custody of the state is not as good as it should be." Another judge indicated a challenge in getting timely affidavits from some health care providers. According to another judge, challenges also included that not all judges know the relevant information and some judges "would love to simply not have to do this."

#### Process

Six (55%) judges indicated that the process for acquiring a *Rogers* Order is a challenge. Of those suggesting this, four (67%) judges felt the current process is altering the behavior of health care providers in unintended and undesirable ways. Two (33%) of the six judges specifically indicated that health care providers prescribe other classes of psychotropic medications in place of antipsychotics to avoid judicial review. Two (33%) other judges commented on the caveat for emergency medications; one indicated that emergency medications were being prescribed under unwarranted circumstances, while the other indicated that emergency prescribing is not happening when warranted. Other challenges with the *Rogers* process included a lack of continuity between placement settings (17%), the process is not adversarial as intended leading to a rubber stamp approach (17%), the need for someone intimately involved in the life of the child to inform judicial review (17%), and the challenge that each step of the process must be completed for a meaningful judicial review (17%). One judge indicated that the use of multiple medications is "extraordinary."

#### • Oversight

Six (55%) judges indicated that oversight is a challenge in the current process. Of these six, four (67%) judges indicated that adequate information is not available to inform oversight efforts. One judge said "...rubber stamping occurs because there is not enough information being provided to the judges. Basically, the judges need some basis for evaluating treatment plans." Another judge emphasized that he "never feels comfortable" rejecting a proposed treatment plan because of the potential consequences of this denial. Of the judges who indicated oversight as a challenge, two (33%) judges suggested that judicial review of only one class of medications, antipsychotic medications, is inadequate. Another noted that health care providers fail to update affidavits despite a legal obligation to do this. Finally, one judge commented on the inadequacies of the current process for monitoring side effects.

## Political

Six (55%) judges suggested that politics and power present challenges in the current process. Of the politics identified, three (50%) of the six judges identified challenges in the relationship between the health care provider and the Juvenile Court. Specifically, judges alluded to the challenge in overseeing health care providers who seek authorization for a range of medications and dosages. Two (33%) judges indicated that other stakeholders (i.e., lawyers, GALs, or social workers) are unable to challenge the authority of health care providers. One judge noted that youth in state custody are at risk to be victimized by this process, as the level of medication review is unequal among youth in state custody and youth in the general population. One judge felt that the process is inadequately adversarial; another stated that the legal authority is not granted to courts to ensure timely submission of affidavits by health care providers.

## • Other Challenges

Lastly, several other challenges were identified by judges but to a lesser extent. Specifically, judges recognized challenges within the domains of: knowledge (45%), resources (36%), and consumers (9%). Major challenges among these domains included a lack of mental health expertise for GALs, inadequate training (specifically on mental health for GALs and social workers), and insufficient financial and human resources for the time intensity of judicial review.

#### **RECOMMENDATIONS**

Recommendations are broken down into two overarching categories: (1) recommendations for the current *Rogers* process and (2) recommendations for substantial change.

## Recommendations for the Current Rogers Process:

Recommendations for improving the current *Rogers* process fell into three domains: (1) knowledge, (2) consumers, and (3) oversight.

## • Knowledge

Nine (81%) judges felt that additional training is needed to improve the current *Rogers* process. Of those indicating the need for additional training, eight (89%) judges identified general training areas for stakeholders involved in the *Rogers* process; specifically, six (67%) judges recommended training in mental health diagnoses, medications, and alternatives, while two (27%) judges recommended training on procedural elements and stakeholder roles in the *Rogers* process. Judges also recommended additional training for the various stakeholders involved in the *Rogers* process, including the *Rogers* GALs (46%), judges (36%), Attorneys (33%), and youth (11%). Judges noted that *Rogers* GALs, especially those without educational experience in mental health care, need additional training on effective treatments for the mental health needs most prevalent among youth in DCF custody. Of particular note, one judge indicated that he would benefit from resources in addition to training sessions, such as a "cheat sheet" with details about psychotropic medications. Finally, participants suggested that attorneys would benefit from having a better understanding of the role that *Rogers* GALs are to play and, accordingly, the appropriate questions to ask the GAL.

#### Consumers

Eight (72%) judges indicated that attention should be given to the way consumers are engaged in the *Rogers* process. Judges emphasized the need for additional consumer engagement in the *Rogers* hearing and in any reviews of the *Rogers* Order after initial authorization is provided. Among those indicating attention to the level of consumer engagement, judges recommended that youth (88%), foster parent (38%), and biological parents (13%) provide additional input into the decision-making process, but indicated that ultimate consent authority should lie elsewhere. Judges generally felt that youth should have more involvement, but only under certain conditions, including youths' ages (from 12 years of age and older), and developmental stages. Two judges indicated the importance of foster parent involvement, as they are frequently the ones "seeing" the child after consent is granted. While recognizing the importance of biological parent involvement as valuable sources of information regarding medical history, three judges also noted that the level of biological parent involvement should vary depending on whether their rights have been terminated. For example one judge state, "I think [biological parents] need to play a role, unless their rights have been terminated. This is still their child. They know the child. They may have been bad for the child, but I want to know what they think."

## • Oversight

Five (46%) judges recommended improving the oversight of psychotropic medications for youth in DCF custody. Of those who indicated improving oversight, three (60%) recommended extending oversight to additional classes of medications (rather than just antipsychotics), especially if a child is on multiple psychotropic medications or on medications with harmful side effects. While they thought extending oversight to other psychotropic medications was important, many indicated concern about where to draw the line if oversight was extended to additional psychotropic medications or prescribing practices.

Of those who suggested improving oversight, a third indicated the need to improve the process for monitoring medications at the child- or case-level. One judge noted that ultimate accountability for the *Rogers* process was not vested in any one person; in response to this concern, the respondent recommended the formation of a DCF *Rogers* Tracker. The respondent recommended that the *Rogers* Tracker would monitor pending *Rogers* cases, ensure reviews occur, and act as a liaison between DCF and the *Rogers* GALs. Specific recommendations included amending the 60-day review process with a 30-day review to be completed by the GAL, and to standardize the approach for monitoring medications. Another respondent recommended that judges acquire consultation with a university-based medical panel on an "as needed" basis.

## Other Recommendations

Lastly, other recommendations fell into the domains of: best interest of child (27%), workforce (27%), process (27%), and resources (18%). Specifically, judges recommended improved coordination among stakeholders.

## **Recommendations for Substantial Change:**

In contrast, two (18%) judges thought the ultimate decision-making authority should reside in an expert panel with psychiatric expertise. For judges who recommended the medical panel, judicial involvement was still deemed important. One judge said, "[I would] only want the judiciary to be involved if there were some kind of question or concern about the process [with the medical panel review]...For example, if someone thinks a child's case should have been reviewed by the panel and wasn't. Or, if a party wanted to claim that the process was not followed correctly, or if a party wants to petition for another review...I do not think that a judge should supplant a medical decision."

In creating a medical panel, some judges expressed concerns, including the ability to finance such a panel, the turnaround time for medication review, and a potentially less rigorous review process if psychiatrists monitor the prescribing practices of other psychiatrists.

#### OTHER STATE AGENCIES

Semi-structured interviews were conducted with two administrators from state agencies other than DCF. Both administrators were located in Metro Boston. In both cases, the administrators were accountable for service delivery across the state. Overall, these administrators indicated a greater number of challenges relative to the identified strengths in the *Rogers* process. Notably, both administrators noted that the process and oversight system were challenges within the current *Rogers* process. A more detailed account of the strengths and challenges identified by these state administrators follows, as well as suggested recommendations to improve the process.

In addition to the interviews with the two state administrators, we also conducted a semi-structured interview and focus group with four members of the Probate and Family Court (including three administrators and one judge). The Probate and Family Court issues *Rogers* Orders under a different set of legal and administrative procedures than the Juvenile Court. Because these staff have limited experience with the *Rogers* process in the Juvenile Courts (which is the focus of this study), these analyses are presented separately to inform potential innovation within the Juvenile Court based on the experiences of the Probate and Family Court.

#### **STRENGTHS**

The majority of the strengths identified by the two administrators fell into four domains: (1) best interest of child, (2) workforce, (3) oversight, and (4) process.

## • Best Interest of Child

One state administrator felt the process is able to meet the best interest of the child. The administrator noted the important role for DMH to evaluate the efficacy of psychotropic medications prescribed for a child receiving services. The administrator said, "...when kids come to us they are on so much medication that it is hard to tell which is working. So we distill that and see what is working and what's not. Our goal is also to decrease the number of medications. Sometimes they discharge without being on any."

## Workforce

One state administrator felt the workforce is a strength of the current process. The administrator indicated the workforce is aware of both the need for oversight of antipsychotics, and their role within the *Rogers* process.

#### • Oversight

One state administrator indicated the oversight offered by the *Rogers* process as a strength. The administrator felt an authorization process for youth in DCF custody is logical, stating, "Now the idea about having a special level of reflection around making special decisions for kids in state custody... makes absolute sense..."

#### Process

One state administrator noted the process for a *Rogers* Order as a strength. The administrator specifically indicated that there is improved compliance in completing the *Rogers* affidavit in acute care outpatient settings.

## **CHALLENGES**

The majority of challenges identified by the two state administrators fell into the following domains: (1) knowledge (2) oversight, (3) process, and (4) political.

#### • Knowledge

The two state administrators indicated that key stakeholders have inadequate training or experiences. Both respondents suggested the need for the judges to have additional expertise in pharmacology. One administrator said, "I think what most concerns me about this process is that it takes the decision-making capacity and affords [the] final decision making around a clinical issue to people with no clinical background." One administrator also indicated the need for the GALs, as well as social workers, to have additional expertise in pharmacology, "My biggest concern about the process is that judges and GALs are not trained in psychopharmacology. It is very important discipline. It requires a lot of medical and psychopharmacology training. It feels like judges don't

have the full picture because they don't have the training. If a layperson looks at the medications, multiple medications, higher doses, of course you might be concerned." One administrator also noted the need for the prescribing health care providers to be experienced mental health care providers.

## • Oversight

Both state administrators felt oversight remains a challenge. Both administrators indicated the need to extend oversight to additional classes of medications. One administrator thought it particularly problematic that the use of multiple psychotropic medications is not always authorized by a third party.

#### Process

Both state administrators stated that the process for the *Rogers* Order is a challenge. One state administrator commented on lengthy responses from the Juvenile Courts, an inconsistent standard of review, and that final decision-making authority should not be vested in someone without a clinical background. The other state administrator noted medications are being prescribed, especially in acute care settings, with expired *Rogers* Orders.

#### Political

Both state administrators indicated that politics are a challenge in this process. One administrator felt the 'inertia' of the existing *Rogers* process is a challenge, "And why is it okay that we created this whole process, with all these people who are invested in it, and now you interview them and of course they want it to continue. That's a standard organizational response. You create an organization it will set itself up to continue." The other administrator indicated that health care providers may be intimidated by the judicial review.

## • Other Challenges

Lastly, other challenges were identified by the state administrators, but to a lesser extent. Specifically, state administrators recognized challenges within the domains of: consumers and resources. Major challenges among these domains are the lack of youth involvement in the *Rogers* process, and the large amount of time required by the health care provider in the *Rogers* process.

#### **RECOMMENDATIONS**

Recommendations are broken down into two overarching categories: (1) recommendations for the current *Rogers* process, and (2) recommendations for substantial change.

## **Recommendations for the Current** *Rogers* **Process:**

Recommendations for improving the current *Rogers* process fell into three domains: (1) consumers, (2) oversight, and (3) process.

#### • Consumers

Both state administrators recommended more consumer engagement than in the current *Rogers* process. Specifically, both administrators indicated the need for additional "youth voice" in the *Rogers* process. One administrator said, "I always think youth voice should be included. They should be part of the meetings and their input should be taken seriously." The other administrator indicated that educating youth about their mental health and the treatment plan should occur. Specifically, this administrator said, "[Youth] need to be well informed or they won't take the medication, and then nobody wins." Both administrators also indicated the need for additional involvement of the biological parent, when appropriate. One administrator said, "... what we see, is kids go back to their biological family when they turn 18. What sense does it make to cut them out when that is what is happening. What kind of relationship can be had with the bio family? Cutting off ties doesn't feel natural, if they are going back to them. It is not black and white. We have a girl here who wants to see her mother and DCF won't let her. She is going to go back to her, probably. What sense does it make to cut her off?"

## • Oversight

Both state administrators recommended changes to oversight. While both state administrators indicated concern about extending oversight to additional medications within the current *Rogers* process (i.e., due to resource limitations and lack of medical expertise), they both also indicated that extending the informed consent review to other classes of psychotropic medications should be a part of reform efforts. One administrator indicated the need to measure impact and process outcomes, "Look at the long term success for kids: are they still violent? Less meds? Hospitalized for shorter periods? Are they going to school? Do they have a friend? Do they see a future for themselves and feel better about themselves? Quality of life scale? Less medical complications, like weight gain and diabetes?"

#### Process

Both state administrators recommended changes to the process of a *Rogers* Order. One administrator recommended adding medical expertise to the current *Rogers* process, whether consulting with a mental health expert or medical review panel. The other state respondent explicitly noted that any changes to the *Rogers* process should not be minor, "Flaws are systemic in current approach, revising this system is not the solution."

#### • Other Recommendations

Lastly, other recommendations fell into the domains of: best interest of child (27%), workforce (27%), process (27%), and resources (18%).

## **Recommendations for Substantial Change:**

One state administrator indicated that ultimate decision-making authority should reside in medicine and not the Juvenile Court. The respondent indicated that a multidisciplinary advisory board, with psychiatric expertise, should be assembled to authorize psychotropic medication use, stating, "...I think having an internal or external process at DCF that includes a multidisciplinary sort of advisory body or a small group of people that can review it that come from pediatrician, child psychiatrists, maybe a clinical social worker, who does therapy...." This participant also indicated the importance of eliciting a shared set of goals from various stakeholders to inform the development of this or any other change to the *Rogers* process.

#### PROBATE AND FAMILY COURT

The Probate and Family Court ("Probate Court") initially adopted the *Rogers* process in 1983 to provide substitute judgment for "incapacitated" adults who required "extraordinary treatment," including antipsychotic medications. The Probate Court continues to hear *Rogers* cases both for adults and a specific group of youth in DCF custody.<sup>1</sup> To learn about the experiences of the Probate Court in administering the *Rogers* process, we conducted a focus group with three legal administrators in the Probate Court ("administrators"), and a semi-structured interview with a Probate Court judge ("judge"). This section describes four features of the Probate Court *Rogers* process identified by respondents as strengths and potential innovations for the *Roger* process in the Juvenile courts: (1) Training, (2) Youth Involvement, (3) Accessibility, and (4) the Standing Order for adult *Rogers* cases (i.e., administrative review of uncontested *Rogers*).

## • Training

The *Rogers* process in the Probate Court requires training of attorneys, GALs, and *Rogers* Monitors. The *Rogers* process in the Probate Court operates according to a fee-generating system that is governed by Supreme Judicial Court Rule 107. The Rule specifies both the

"We have the most comprehensive system for what each of the categories is and each of the categories [has] a requirement for training and procedure" -Probate Court Administrator

training and the procedural requirements for the *Rogers* Monitor, the GAL, and the attorneys during the *Rogers* process. With regard to training, the Rule specifies that the *Rogers* Monitor and GAL must complete two courses each year (six credits total). For the *Rogers* Monitor and GAL, third party vendors provide the training and Massachusetts Continuing Legal Education credits are awarded. Attorneys are also required to receive a 4-hour training offered by the Committee for Public Counsel Services. The Probate Court requires documentation of credits. Respondents indicated that training to agency staff or consumers is not required as part of this feegenerating system, and is, therefore, left to the discretion of agency staff or consumers.

## • Accessibility

The administrators and the judge indicated that the Probate Court is able to prioritize *Rogers* cases, especially for youth, due to the relative infrequency of these Probate Court hearings. Respondents indicated that cases are frequently held at the time of day most convenient for stakeholders. The flexibility of the Probate Court to accommodate the schedules of stakeholders helps ensure the participation of the *Rogers* monitor, GAL, attorneys, as well as the child and health care provider (when their respective testimonies are needed).

## • Youth Involvement

Both the administrators and the judge indicated the need to place priority on youth involvement in the *Rogers* process, especially during the hearings. The judge and an administrator referenced that the degree of direct involvement by a child needs to be responsive to both age and developmental stage. Within the Probate Court, youth involvement in the *Rogers* process is codified in Article 5 of the Uniform Probate Court.

"[Youth] are entitled to be a part of the Rogers process. Article 5 of the UPC actually says that now. ... If [the child is] able to participate at a higher level, then the judge might actually ask them [to participate directly]. I have been in situation[s] with 15 or 16 years old[s], when the judge actually talks to the child[ren] about taking their medication, with the child's lawyer's permission. The judge will say, 'I understand that you are not taking your medication. Do you want to talk to me about what's wrong and why you are not taking it?' And the child will say, 'Well, it makes me gain weight.' Or you can have children who are not able to articulate or engage at all. So, they are unable to participate directly. It really runs the gamut."

-Probate Court Administrator

<sup>&</sup>lt;sup>1</sup> The Probate and Family Court does provide judicial approval for psychotropic medication use for a relatively small number of youth in DCF custody pursuant to M.G.L. Chapter 119, Sec. 23(a).

• Standing Order 4-11 (for Adult cases only)

In July 2011, the Probate Court rolled out the <u>Massachusetts Probate and Family Court Standing Order 4-11:</u> Administrative Process for Uncontested <u>Rogers Reviews and Extensions</u> ("standing order"), which provides an administrative review process for "extraordinary treatment," including antipsychotics, that is uniform across the state. The review is conducted by a judicial designee, who is not a judge, for uncontested <u>Rogers Orders.</u> The standing order may be used for 'incapacitated' adults only (not youth) who have been under guardianship for at least one year. The process vests the authority to approve antipsychotic medications to a judicial designee when the administration of antipsychotics is not contested. The prescription may be contested by a stakeholder in the <u>Rogers process</u>, and will then require a judicial hearing. The judicial designee may also determine the need for judicial review if any concerns arise in the administrative review. The standing order includes standardized forms as well as a series of timeframes for particular events, such as receipt of the medical report from the clinician.

One administrator noted that the standing order may, in fact, create a systematic process for administrative review of antipsychotics that will be an improvement over the judicial review process.

"The administrative review of uncontested matters has-to some extent- the potential to be more thorough than scheduling a lot of five minute courtroom hearings. If you set up 20 Rogers reviews in the court room and a stack of files for the judge- who just had a motion session yesterday- and [the judges] are being asked to go through the Monitor's report, the attorney's affidavit, the treatment plan and everything else... the judge certainly will do it, and I am not saying what may or may not happen. But, structurally you can create opportunity for a more thorough review with a process with all the safeguards. And of course, the people appointed from our list ...many times are people with whom [the] court has experiences...and likes their work."

- Probate Court Administrator

While the Probate Court administrators expressed the merits of this process for review of "extraordinary treatment," the judge indicated concern that the standing order would be "less thorough" than the current process for judicial review.

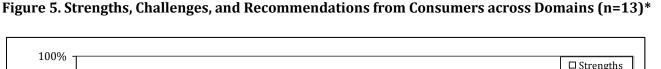
#### **CONSUMERS**

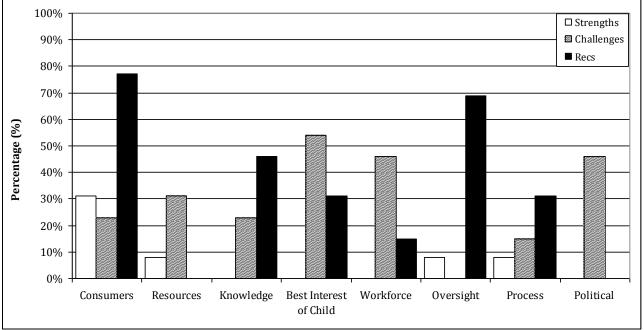
Semi-structured interviews were conducted with 13 consumers who were or had been caregivers of youth in DCF custody (i.e., biological parents, adoptive parents, foster parents and kinship caregivers such as grandparents). Three focus groups also were conducted with a total of 12 youth who had aged out of state custody. (*Note*: Focus group respondents' comments were not included in proportions presented in the figure as responses are not independent of the group process and, as such, cannot be summarized as counts.)

Despite significant efforts to recruit consumers by the NUSL students and the Tufts Research Team, additional efforts are necessary to ensure the diverse perspectives of consumers, including both caregivers and youth, are represented. The recruitment of the consumer sample included contacting foster parent associations, caregivers active to DCF consumer involvement advisory boards, DCF youth workers working with youth aging out of the system, youth in the Foster Club, youth in transitional care units, and young adult alumni of the system. Whether our challenges in consumer recruitment were a function of our recruitment processes, geographic variation in consumer involvement, or evidence of a lack of overall consumer involvement in the *Rogers* process, cannot be determined from the available data. We recommend a prospective study in the future, interviewing consumers, including youth, immediately following court hearings to garner feedback on the process.

It should be noted that most of those interviewed did not have first-hand experience with the *Rogers* process, even if they had experience with antipsychotic medications. Only two of the 25 respondents in both the semi-structured interviews and focus groups could recall participating in a *Rogers* process or going through a court process around medication use.

Overall, consumers did not point to many strengths of the *Rogers* process. In their discussion of challenges, most participants referred to experiences they had with foster youth on medication. In discussing their experience with youth on medication, many of the respondents had strong opinions about the informed consent process. The top recommendations identified by consumers involved improvements in the domains of (1) consumer engagement, (2) oversight, (3) knowledge, (4) process, and (5) best interest of child.





<sup>\*</sup>Note: Recs = Recommendations. Proportions displayed in this figure do not include the 12 youth focus group participants.

#### **STRENGTHS**

As most consumers did not recall any participation in the *Rogers* process, respondents were asked about theoretical strengths of the process. The potential strength most identified by consumers was parent/family involvement (31%). One foster parent with experience with the *Rogers* process also identified this strength; she noted that her role was to contact DCF to get a court date. A biological parent remembered feeling trusted as a part of a competent team and having a positive experience.

In general, youth did not point to any strengths of medication oversight processes experienced while in DCF. They did however, articulate their resilience and commitment to being engaged in the decision-making process.

"It's time for everything to change. You need to let the kids decide whether they want to take it or not because you don't know what that kids is capable of before you put them on the pill. If you're just going to throw them on medication, do you think of 'what's best for that child [is] putting him on medication' or you don't care about that child and you just put him on."

-Youth

#### **CHALLENGES**

Again, as most respondents had not actively participated in the *Rogers* process, challenges raised were mainly with respect to medication oversight in general. These fell primarily in the categories of (1) best interest of child, (2) workforce, and (3) political.

## • Best Interest of Child

Over half (54%) of consumers expressed concerns that the process is not functioning in the best interest of the child because of problems with quality of care. Half of these respondents thought that a child's best interest is not met because they do not receive proper care. One pointed to the lack of psychiatrists. A few questioned whether the child is receiving the proper diagnosis and whether there are alternative ways to treat the child besides medication. These respondents wanted youth to be assessed holistically and attention placed on all their emotional and behavioral health needs. A child may, perhaps, need therapy instead of medication or a more appropriate placement. Sometimes the placement is not appropriate and causes the child more trauma. A majority (85%) of participants who highlighted quality of care as a concern pointed to the adverse side effects that a child may experience when taking antipsychotic medications. Many felt as though these medications are "over-prescribed" and a quarter of respondents were not convinced of the efficacy of antipsychotics. Half of these respondents remembered incidents where medication did not seem to be effective. One person likened the process of determining medication to that of "shooting in the dark." Another consumer expressed frustration with the process of trying different medications on a child, calling the process "experimentation." One consumer reluctantly agreed to the potential efficacy of antipsychotics, but wanted them to be a "last resort" medication, not a first-line intervention.

The youth in the focus groups also acknowledged the adverse side effects of taking some antipsychotics. Some of them remembered having been informed about potential side effects, while others were not. A few youth also felt it was possible for them to learn how to control their moods without medication. Some expressed frustration because they felt health care providers often prescribe medication even before getting to know all the issues affecting them. Others were concerned that no adults in their lives asked about side effects. One young woman reported enjoying school prior to being put on an antipsychotic and then feeling heavily sedated and experiencing a significant drop in her self-esteem and success in school; she reported it taking "too long," nearly three months, for these side effects to be addressed.

## Workforce

About half (46%) of consumers recognized workforce and health care provider issues as challenges to the *Rogers* process. Forty-two percent of these respondents thought that health care providers have caseloads that are too

large to really know the youths and understand their needs. One participant was very skeptical of health care providers and described those that work with foster youth as "low-end doctors." Some believed that there are too few providers working with youth in DCF. Concerns were also raised about the ability of DCF caseworkers to understand the needs of the child within the family.

## • Resources

A third (31%) of consumers pointed to the lack of resources as a challenge. One parent recalled an experience in which her daughter needed to be on an antipsychotic. However, due to the length of time it took to finally get the approval, the physician put the daughter on another medication, causing her to experience adverse side effects.

## • Consumers

Approximately a quarter (23%) of consumers saw lack of consumer engagement as a challenge to an effective process. One parent voiced that DCF never told her they were going to go to court. Another parent, who expressed wariness regarding DCF, portrayed the lack of involvement as a "deliberate" action on the part of DCF. This parent was particularly concerned that fathers are stigmatized in the current system and are not seen as an important part of the medication decision-making process.

Youth strongly voiced their frustration with not being better informed during the *Rogers* process. Some youth felt as though they were prescribed medication without being given full information, including potential benefits, risks, and side effects. This dynamic made one youth feel like a "lab rat." Of those youth with experiences taking antipsychotic medication, only one could remember talking to a judge or attorney during the decision-making process for treatment.

#### Knowledge

Twenty-three percent of consumers voiced that other caregivers, such as themselves, were in need of additional training in areas related to mental health care and treatment for youth in DCF custody. In addition to information about what the *Rogers* process actually entails, consumers noted that they could also benefit from education on trauma and how it affects youth. Last, consumers recognized the challenge of understanding the benefits and risks of antipsychotics and how to best monitor its effects on youth.

Some youth also focused on the knowledge base of the judiciary and the qualifications that judges have to make medical decisions. Because judges typically do not have a medical background, some youth were skeptical as to the appropriateness of judicial review and decision-making around mental health treatment, as well as to the types and dosages of antipsychotic medications.

#### Political

Approximately half (46%) of consumers described political and power issues between them and other stakeholders as a challenge to medication oversight. Sixty-six percent of these respondents admitted that they are intimidated by health care providers, DCF workers, and attorneys, feeling that their perspective as biological or foster parent is not trusted.

#### RECOMMENDATIONS

Recommendations are presented in two overarching categories: (1) recommendations for the current *Rogers* process, and (2) recommendations for substantial change.

## **Recommendations for the Current** *Rogers* **Process:**

#### Consumers

Consumer engagement emerged as the most common recommendation cited by participants. Over three-quarters of consumers believed that youth and parents should be more involved in the *Rogers* process. Of these participants, the most cited reason (70%) for youth being involved was that they can give input into how a medication is working and identify side effects. There was little consensus as to the appropriate age for youth involvement, with some advocating for youth as young as age 12 years and others believing that only older youth

should have a say. Though consumers advocated for more youth involvement, they did not necessarily believe that youth should have ultimate decision-making authority.

Youth interviewed felt they should have a say in the process, with one youth advocating that young people should have ultimate decision-making authority over their medication use. Youth expressed that not being part of the decision process reinforced a sense of powerlessness, "There's a lot of kids that are tired of being stepped on, hurt and not listened to." Youth believed that in order for a judge to understand their situation, the judge needed to speak to the child and understand the situation holistically. Judges should not just listen to those deemed "experts" such as health care providers, but should view the youth as experts on their own well-being. Several youth specifically recommended that health care providers should regularly monitor prescribed medication. One child summed up the sentiment of others with the following remark, "If you don't have the kid's opinion about what he may like or dislike about it or why he may not want to take it then how do you know what's good for him unless you sit there and talk to him some?"

Consumers also advocated for a greater role of biological and foster parents in the *Rogers* process. Sixty percent of participants recognized the role of foster parents in helping monitor the child, especially with respect to medication and potential side effects. One participant pointed to the responsibility of foster parents to watch out for the well-being of the child, "I see my role as being very important because when you think about the contact with the child, most of the hours of the day the child is with you, the foster parent. My role would be to note what happens in the home, note what happens outside the home, and know what's going on in school." Those who thought biological parents should have a role (40%) cautioned that the designated role should be on a "case by case" basis. These participants remarked that "it depends" on the situation of the parent, noting that some biological parents struggle with their own mental health challenges. Some of the youth also expressed skepticism about the involvement of biological parents for similar reasons.

## • Oversight

Sixty-nine percent of consumers acknowledged a need for medication oversight; however, there were varying opinions on who should provide this oversight. Suggested stakeholder groups for providing oversight included: external review board (33%), health care providers (33%), judges (33%), state agency/DCF (22%), and parents (1%). One participant, who believed in the current role of the judiciary, thought judges should have ultimate oversight, noting, "The foster parent doesn't really want to respond and take care of the child. I truly think the judge should make that decision based on how bad the situation is and not just take DCF's word." Those who did not support judicial review pointed to the judge's lack of clinical knowledge. One third of consumers advocated that ultimate decision-making authority lie with an external review board. Those who thought DCF should have ultimate oversight believed that DCF is in a position to get a "holistic assessment of the child from multiple stakeholders".

There were conflicting views about which medications should be included in the *Rogers* process. Two parents wanted all antidepressants and mood stabilizers to be included. One parent thought monitoring should be by dose, "If you do higher doses or mix meds, that's when you have to be careful. Children can be on a variety of meds. And they're added at different junctures. Those are the things I hear that cause the worst issues. I would shift the process to be dosage and polypharm specific." Contrastingly, some participants cautioned against adding more medications. A foster parent voiced that including non-antipsychotics would "tie up the court system." This same participant thought that having on-going monitoring could avoid many of the problems. Further, a foster parent did not think "most meds would need that kind of scrutiny."

#### Knowledge

Almost half of the consumers pointed to the need for more training and knowledge of those working with the *Rogers* process. The following stakeholder groups were identified as needing more training: judges (50%), foster parents (50%), and DCF social workers (33%). Judges need training on "the nature of these cases." Foster parents need training on the *Rogers* process itself. DCF social workers need training on "how to treat children."

#### Process

Thirty-one percent of consumers felt the process was too complex. One participant remarked, "Make it simpler. We've got so many pieces. I'm unconvinced that the right pieces are there and effective. It doesn't seem like an effective process at this point. The people who know the meds best are docs and experienced parents. I'm not sure that the expertise or the approvals they're seeking adds much to that - except that it adds oversight. But there's not a reporting structure to know if it's working or not. They've added all of these steps and everything without actually checking up on it. The process seems so non-rigorous."

## • Best Interest of Child

Thirty-one percent of consumers believed that there should be better strategies for representing the interests of youth and quality of care. Of these, 50% felt there should be a team approach to caring for the child. Addressing the overall well-being of a child requires conversation and coordination among doctor, pharmacist, DCF social worker, psychiatrist, and primary care physician. Half of these participants also felt that youth are being overmedicated and there should be a more comprehensive way of addressing a child's mental health needs. One participant cautioned, "Not everything is about meds. It's about finding out what they want, if they want to go home, and be with their families. All that needs to be monitored." Similarly, a few of the youth saw medication as an "easy way out" for addressing other pressing issues that youth in state custody are facing.

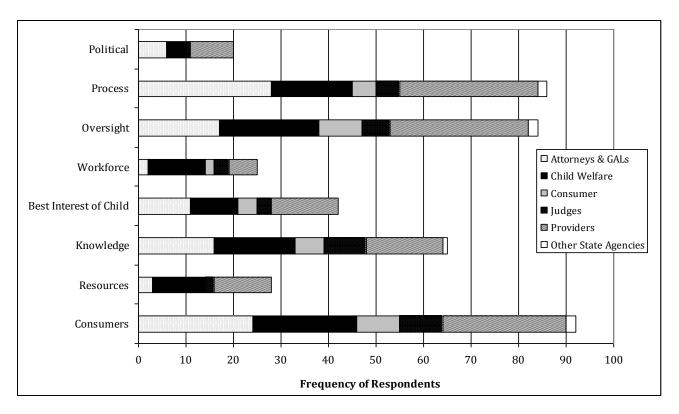
## **Recommendations for Substantial Change:**

There were three recommended changes to the *Rogers* process made by consumers: (1) a team approach to care for the child (31%), (2) eliminating the role of the judiciary (38%), and (3) having an on-site psychopharmacologist at DCF (15%). Consumers felt the current process does not serve the needs of the child. Taking a team approach would ensure that there are multiple eyes on the child and that a comprehensive approach was taken to care for the child. Consumers also recommended elimination of the role of the judiciary on the grounds that judges do not have the proper background to provide medication oversight. There was also distrust of judges who did not speak to youth and their caregivers. The existence of a medication oversight expert on-sight at DCF would eliminate the bureaucratic challenges of the *Rogers* process.

# Summary of Recommendations across Stakeholder Groups

Figure 6, below, provides a schematic of the types of recommendations made across the eight categories developed by the research team after reviewing data from the five stakeholder groups (in this illustration, however, the legal stakeholder group has been broken down into "Attorneys & GALs" and "judges."). These data were used to derive the five overall recommendations provided in the full *Study Report*.

Figure 6. Cumulative Frequency of Stakeholder Recommendations across Domains (n = 109)



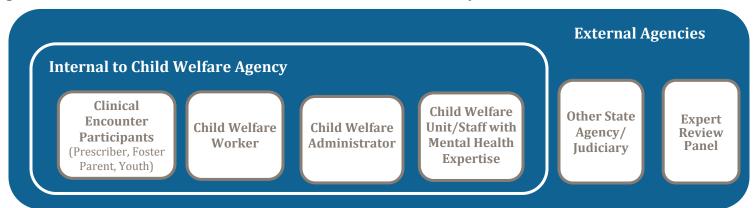
As is illustrated by Figure 6, the recommendations that were made with the highest frequency included: (1) consumers, (2) process, (3) oversight, and (4) knowledge. From the recommendations made within process, oversight, and knowledge categories, increasing medical expertise within the *Rogers* process was a prevalent theme that emerged. Consequently, to provide adequate coverage of this recommendation it was expounded from the others.

Please refer to the *Study Report* for a more detailed account of these recommendations.

# **State Summaries of Informed Consent Systems**

States vary in their approaches to obtaining informed consent for psychotropic medication use for youth in child welfare custody. State child welfare agencies designate one or more persons with the authority to **authorize** prescribing psychotropic medications for youth in custody. Some state agencies also have a mechanism in place to **review** the request to administer psychotropic medications prior to authorizing their administration to an individual child. Different categories of people or agencies may play a part in **reviewing the request** to administer psychotropic medications. Review may be conducted by agencies external to the child welfare system (e.g., other state agencies, judiciary, and an expert review panel) or by individuals or units from within the child welfare agency (e.g., clinical encounter participants, child welfare workers, child welfare administrator, and a specialized unit or staff with mental health expertise) (see Figure 6).

Figure 6. Location of Medication Review within the Informed Consent System



States also designate different units, both internal and external to the state agency, with the ultimate decision-making authority for consenting to the administration of psychotropic medications. California is the only other state in the country that vests decision-making authority and review within the judiciary. Notably, California includes all psychotropic medications in its review process. Because of this, we selected California as one of the four states to review. The other three states we have selected—Connecticut, Illinois, and Texas—represent three unique models for both reviewing the request and authorizing the administration of psychotropic medications (see Table 1).

Table 1. Four States: Ultimate Decision-Making Authority and Prescription Review

State	Primary Decision-making Authority	Prescription Review*
California	Judiciary	Judiciary
Connecticut	Child Welfare Unit/ Staff with Mental Health Expertise	Child Welfare Unit/Staff with Mental Health Expertise
Illinois	Child Welfare Administrator	Expert Review Panel; Child Welfare Staff with Mental Health Expertise
Texas	"Medical Consenter:" Typically the child welfare worker, but may also be biological parent if parental rights are not terminated, foster parent, or any other person determined to be able to consent to medical care that is in the best interest of the child.	After authorization of medications, both a contracted health network and staff with mental health expertise will review psychotropic medications dispensed.

<sup>\*</sup>Prescription review occurs before authorization of prescribed medications, unless otherwise noted.

As described in the four state summaries provided below, most states' systems of informed consent differ in a few key ways: (1) the informed consent process, including the decision-making authority (i.e., who is responsible for this process, and where this responsibility is housed) and the prescription review process (i.e., who informs the decision to begin or change medications); (2) the exceptions made to this process to provide additional oversight for certain populations (e.g., youth in residential placement) and to ensure youth engagement in the process of beginning or changing psychotropic medication use; (3) the appeal process when prescribed medications are contested; and (4) the process for monitoring the provision of informed consent for youth in child welfare custody.

The following state summaries are offered to provide an overview of their respective systems. For simplicity sake, summaries below may not be specific as to all exceptions for the informed consent system.

We collected these documents through a document review and key informant interviews. We collated and reviewed data from state websites and publicly available documents for each of the four selected states. We also conducted four key informant interviews with a representative from each of the selected states. More specifically, key informants were mid-level managers knowledgeable about the state system for oversight of psychotropic medications. Key informants from each of the four states were also contacted to respond to particular questions about their respective informed consent systems.

#### **CALIFORNIA**

#### **OVERVIEW OF SYSTEM**

The California legislature designates the Juvenile Court with the authority to consent for the administration of psychotropic medications to youth in foster care.<sup>2</sup> The judiciary has, in turn, provided a minimal set of parameters for judicial oversight across the state.<sup>3</sup> Within these parameters, many California counties then endorse rules specific to their county.<sup>4</sup>

When a psychotropic medication is prescribed to a child in foster care, the health care provider is responsible for submitting a request to the appropriate county-level child welfare agency.<sup>5</sup> The appropriate county-level agency must, in turn, submit an order to the Juvenile Courts.<sup>6</sup> Select stakeholders, including, the parent or guardian, his or her attorney, the child's attorney, or the child's Child Abuse Prevention and Treatment Act guardian *ad Litem* (CAPTA GAL), may oppose the request to prescribe psychotropic medications.<sup>7</sup> Court Appointed Special Advocate volunteers (CASA) will advocate on behalf of the best interest of the child. Without consulting the parties, the judge can make a decision to approve, deny, modify and order the authorization. The judge will also conduct a hearing in cases where the request is opposed.<sup>8</sup>

# Table 2. Key Stakeholders

Stakeholder	Role
Juvenile Court	Designated with authority to consent for the administration of psychotropic medications to youth in foster care.
CASA Volunteer	Advocates on behalf of the best interest of the child

The following summary reviews the process for authorizing the administration of psychotropic medication to youth in foster care, including exceptions to this process, the appeal process, and monitoring system. This summary focuses specifically on the minimal requirements set for the state in the California Rules of Court and does not consider processes specific to each county.

#### **INFORMED CONSENT PROCESS**

When a health care provider treating a child in foster care in California wishes to prescribe psychotropic medication, the health care provider must submit a request for authorization to the appropriate child welfare agency according to county procedure.<sup>9</sup> That agency must finalize the request and submit an application for authorization to the court. The state statute encourages the agency to finalize the application within three business days of receiving the request from the physician.<sup>10</sup> The judge issues an order in writing within seven days of receiving a completed application.<sup>11</sup> The judge must approve, deny, or modify the application for authorization or set the matter for a hearing by order of

<sup>5</sup> California Rules of Court 5.640(c)(5)

<sup>11</sup> Cal. Welf. Inst. Code §§ 369.5(c), 739.5(c). California Rules of Court 5.640(c)(4)

<sup>&</sup>lt;sup>2</sup> California Rules of Court 5.640 applies to children declared dependents of the court and removed from the custody of the parents or guardian, as well as, children declared wards of the court and removed from the custody of the parents or guardian.

<sup>&</sup>lt;sup>3</sup> California Rules of Court 5.640. Psychotropic Medications

<sup>4</sup> Id. at (c)(3)

<sup>&</sup>lt;sup>6</sup> California Welfare and Institutions Code §§ 369.5, 739.5

<sup>&</sup>lt;sup>7</sup> http://www.courtinfo.ca.gov/rules/index.cfm?title=five&linkid=rule5\_662 for CAPTA Guardian and http://www.courtinfo.ca.gov/rules/index.cfm?title=five&linkid=rule5\_655 for CASA Volunteer Program requirements.

<sup>&</sup>lt;sup>8</sup> California Rule of Court 5.640 Psychotropic Medications (d)

<sup>&</sup>lt;sup>9</sup> California Welfare and Institutions Code §§ 369.5, 739.5, California Rules of Court 5.640(c)(5).

<sup>&</sup>lt;sup>10</sup> California Welfare and Institutions Code §§ 369.5, 739.5. *Application Regarding Psychotropic Medication* (form JV-220) may be completed by the prescribing physician, medical office staff, child welfare services staff, probation officer, or the child's caregiver, *Prescribing Physician's Statement-Attachment* (form JV-220(A)) are filed by the physician and included with *Proof of Notice: Application Regarding Psychotropic Medication* (form JV-221), and *Order Regarding Application for Psychotropic Medication* (form JV-223) and when applicable *Opposition to Application Regarding Psychotropic Medication* (form JV-222).

the court.<sup>12</sup> Notice of the application must be provided to the parents or legal guardians and their attorneys, the child's current caregiver and CASA volunteer, the child's attorney and CAPTA GAL. The parents or legal guardians, child's attorney, or the court, upon its own motion may schedule the application for a hearing.<sup>13</sup> Notice of an order must be provided to the same parties required to be notified of the application.<sup>14</sup> An order must be reviewed and new authorization issued at least once every 180 days and any time modifications are requested.<sup>15</sup> At the judge's discretion the case may be revisited, and a progress review set for the parties and attorneys to appear before the judge or submit a report for the court's review.<sup>16</sup> Training for judges varies by county with no minimal standard set in the California Rules of Court.

#### **EXCEPTIONS**

Psychotropic medications may be administered without court authorization in emergency situations.<sup>17</sup> To qualify as an emergency situation, the prescribing health care provider must determine that it is both impractical to obtain authorization from a judge and that the administration of psychotropic medication will: (1) protect the life of the child or others, (2) prevent serious harm to the child or others, or (3) treat current or imminent substantial suffering.<sup>18</sup> Court authorization must be sought no later than two court days after the emergency administration of psychotropic medication.<sup>19</sup>

The court may delegate its authority to consent to a parent when such delegation is appropriate.<sup>20</sup> The order is based on whether the parent poses a danger to the child, has the capacity to understand the request and the information provided, and to authorize the administration of psychotropic medication to the child, consistent with the best interest of the child.<sup>21</sup>

Youth in foster care do not have the right to consent to the administration of psychotropic medications at any age.<sup>22</sup> However, they retain the right to refuse psychotropic medications at any age, although the strength of the refusal is likely minimal at a very young age and may be overridden by the court.<sup>23</sup>

#### **APPEAL**

A parent or guardian, his or her attorney of record, a child's attorney of record, or a child's CAPTA GAL may file a completed *Opposition to Application Regarding Psychotropic Medication* within two court days of receiving notice of the pending application for psychotropic medication.<sup>24</sup> The judge will consider such opposition in making the determination whether to authorize the use of psychotropic medication.

<sup>&</sup>lt;sup>12</sup> California Rules of Court 5.640(c)(4)

<sup>&</sup>lt;sup>13</sup> Cal. Welf. Inst. Code §§ 369.5, 739.5

<sup>&</sup>lt;sup>14</sup> California Rules of Court 5.640(c)(4)

<sup>&</sup>lt;sup>15</sup> California Rules of Court 5.640(f) Continued Treatment. Leslie, LK, Mackie, TI, Dawson, E, Bellonci, C, Schoonover, D, Rodday, AM, Hayek, M, and J Hyde. Multi-State Study on Psychotropic Medication

Oversight in Foster Care. Clinical and Translational Sciences Institute, Tufts University Medical Center. Boston, MA: 2010. 
<sup>16</sup> Id.

<sup>&</sup>lt;sup>17</sup> California Rules of Court 5.640(g)(1)

<sup>&</sup>lt;sup>18</sup> Id. at (g)(A)(B)(C)

<sup>19</sup> Id.

<sup>&</sup>lt;sup>20</sup> California Rules of Court 5.640 (e) Delegation of Authority. Leslie, LK, Mackie, TI, Dawson, E, Bellonci, C, Schoonover, D, Rodday, AM, Hayek, M, and J Hyde. Multi-State Study on Psychotropic Medication Oversight in Foster Care. Clinical and Translational Sciences Institute, Tufts University Medical Center. Boston, MA: 2010.

<sup>&</sup>lt;sup>21</sup> Id.

<sup>&</sup>lt;sup>22</sup> Leslie, LK, Mackie, TI, Dawson, E, Bellonci, C, Schoonover, D, Rodday, AM, Hayek, M, and J Hyde. Multi-State Study on Psychotropic Medication Oversight in Foster Care. Clinical and Translational Sciences Institute, Tufts University Medical Center. Boston, MA: 2010.

<sup>23</sup> Id. See also;

<sup>&</sup>lt;sup>24</sup> California Rules of Court 5.640 (c)(8)

#### **MONITORING**

The Child Welfare Services Case Management System (CWS/CMS) measures the percent of youth in foster care who have obtained a court order or parental consent to receive psychotropic medications. In addition, the Welfare and Institutions Code requires that each child placed in foster care has a health and education record that includes current medications, including those prescribed to manage mental health conditions.<sup>25</sup> However, the California child welfare system does not have a mechanism to monitor the provision of informed consent at an individual level. The court retains a record of authorization orders but does not report or maintain such authorizations in a statewide database.

<sup>&</sup>lt;sup>25</sup> All County Information Notice No. 1-20-08 Psychotropic Medications

#### CONNECTICUT

The Connecticut DCF is charged with the authority to consent for administration of psychotropic medications for youth in foster care. The DCF Medical Director delegates to the Centralized Medical Consent Unit (CMCU) and the Regional Medical Directors (RMDs) the authority to provide consent for the administration of psychotropic medication for youth in foster care.

The CMCU is composed of three Psychiatric Advanced Practice Registered Nurses (APRN); each APRN is assigned to one of three regions in the state.<sup>26</sup> The CMCU receives and reviews requests for administration of psychotropic medications to youth in foster care, administers informed consent in select cases, and monitors the provision of informed consent. In addition to the CMCU, each of the three regions has a RMD, who is a board-certified child and adolescent psychiatrist located at a regional office. The DCF Medical Director is consulted by the RMD in cases of involuntary administration of psychotropic medications, and as otherwise needed. To disseminate the protocol for informed consent, DCF publishes the *Guidelines for Psychotropic Medication Use in Children and Adolescents* semi-annually.<sup>27, 28</sup>

# **Initiating Change**

In 2005, the Connecticut legislature mandated that DCF create a "state of the art medication management system for children and youth in custody of the [DCF] Commissioner." In response, DCF endorsed a policy, entitled *DCF Policy 44-5-2: Psychotropic Medications: Informed Consent*, and established the CMCU medical provider-based program housed within DCF.

# Table 3. Key Stakeholders

Stakeholder	Role
DCF Medical Director	Designates the CMCU and RMD to authorize consent for psychotropic medication administration for youth in foster care. Consulted by the RMDs in cases of involuntary administration of psychotropic medications.
Psychiatric Advance Practice Registered Nurse (APRN)	Assigned to one of three regions to administer informed consent in select cases, and monitor provision of informed consent.
Regional Medical Director (RMD)	Board-certified child and adolescent psychiatrist located at one of three regional offices.

#### **INFORMED CONSENT PROCESS**

The informed consent process for youth in foster care occurs: (1) when a health care provider prescribes a psychotropic medication for the first time to a child in foster care or, (2) when a health care provider prescribed psychotropic medication(s) *before* the child enters into foster care or a new placement.

When a child in foster care is prescribed new medications, the health care provider submits the *Request for Psychotropic Medications (DCF-Form 465)* to the CMCU.<sup>29</sup> This request is intended to describe the child's current needs and conditions. Once the request is received, the CMCU verifies the demographic information, Area Office, and child's legal status in the LINK database, DCF's State Automated Child Welfare Information System. If the description provided is unclear, the CMCU requests additional information. The CMCU then enters the request and any additional

 $<sup>^{26}\,</sup>http://www.ct.gov/dcf/lib/dcf/behavorial\_health\_medicine/pdf/cmcu\_contact\_list2.pdf$ 

<sup>&</sup>lt;sup>27</sup> *Guidelines for Psychotropic Medication Use in Children and Adolescents*, DCF Psychotropic Medication Advisory Committee, Department of Children and Families, January 2010. (<a href="http://www.ct.gov/dcf/cwp/view.asp?a=2558&q=386456">http://www.ct.gov/dcf/cwp/view.asp?a=2558&q=386456</a>)

<sup>&</sup>lt;sup>28</sup> Connecticut Department of Children and Families Website, http://www.ct.gov/dcf/cwp/view.asp?a=2639&Q=395016

<sup>&</sup>lt;sup>29</sup> http://search.usa.gov/search?affiliate=ct-dcf&v%3Aproject=firstgov&query=form+465

information into the medical section of the LINK database. Provided certain criteria are met, the APRN will approve and authorize consent. If the APRN is not authorized to approve the prescribed medication, s/he sends the request to the RMD. The RMD then consults with relevant parties (e.g., social worker, DCF Medical Director) to gather further information. In these cases, the RMD determines whether or not to authorize consent, and s/he notifies the CMCU of his/her decision. The CMCU then records and forwards the authorization to the prescriber and other interested parties that require notification. A response must be issued by CMCU within 24 hours of receiving the request.

Youth entering foster care or new placements may already be taking psychotropic medications. In these cases, DCF and the CMCU will determine when informed consent was obtained. If this cannot be determined, the CMCU follows the usual procedure detailed above; however, the request (i.e., *DCF-Form 465*) is submitted with an indication to "Continue Current Medication Only," and an expedited decision must be made within 12 hours. In this informed consent system, it is not necessary to interrupt the child's medication regime while consent is obtained.

A new informed consent form is *not* required for dosage changes, provided these fall within the parameters of the initial approved request. In addition, discontinuation and tapering of medication do not require consent, although discontinuation must be reported and recorded at the CMCU. Guidelines and written policy do not specify how long the CMCU consent remains valid.

#### **EXCEPTIONS**

According to DCF policy, youth consent is not required at any age, and a child may refuse psychotropic medication at age 14. A key informant noted that, in practice, youth consent is obtained at age 16, and youth have the right to refuse at any age.<sup>30</sup> In cases of refusal, however, DCF policy stipulates that medications may be involuntarily administered with additional medical and legal review. Specifically, a second opinion is sought from a DCF-contracted physician who determines whether or not administration of the medication is both medically necessary and in the best interests of the child.<sup>31</sup> If the child's health care provider, the DCF Medical Director, and the DCF-contracted physician are all in agreement that the medication should be administered involuntarily, the recommendation of the DCF Medical Review Board is sought.<sup>32</sup> If the Medical Review Board also recommends involuntary administration, the assigned attorney from the DCF Office of Legal Affairs is consulted and contacts the Office of the Attorney General to initiate an application for a court order for the involuntary administration of psychotropic medication against the patient's wishes. A court order is not sought if there is disagreement between the independent psychiatrist and the DCF physician. The Commissioner will make the final decision about seeking a court order if there is agreement between the prescribing doctor and the DCF-contracted physician, but disagreement by the Medical Review Board or by the DCF Medical Director.

CMCU notification is necessary for all intramuscular administration of psychotropic medications. CMCU notification must occur within 12 hours of a child receiving medication on an emergency basis.

### **APPEAL**

The decision of the CMCU or the RMD is final, unless the prescriber submits a written or verbal appeal. In this case, the DCF Medical Director may be asked to make a final determination. The DCF Medical Director contacts the prescriber to discuss the case and to make a decision. The final decision is recorded by the APRN in the LINK database, and the prescriber is notified of the outcome. The decision of the DCF Medical Director is final.

### **MONITORING**

DCF has established a separate database to monitor the administration of informed consent for psychotropic medications to youth in foster care. The database allows the CMCU to track informed consent for psychotropic

<sup>&</sup>lt;sup>30</sup> Data from the 2010 multi-state study on psychotropic medication oversight in foster care conducted by L.K. Leslie (PI) at Tufts Medical Center

<sup>&</sup>lt;sup>31</sup> DCF Policy 44-5-2.2; Involuntary Administration for Psychotropic Medication to Committed Children, http://www.ct.gov/dcf/cwp/view.asp?a=2639&Q=459880

<sup>&</sup>lt;sup>32</sup> The Medical Review Boards composition is unclear from DCF policy and the Guidelines

medications and to review prescriber patterns by placement, discipline, region, or individual clinician. <sup>33</sup> DCF policy and guidelines do not indicate any timeline for *routinely* monitoring informed consent for psychotropic medication use among youth in foster care.

 $<sup>{\</sup>it 33} http://www.dcf.state.fl.us/initiatives/GMWorkgroup/docs/PsychotropicMedicationManagementYouthStateCare.pdf$ 

#### **ILLINOIS**

#### **OVERVIEW OF SYSTEM**

The Illinois Department of Children and Families Services (DCFS) is charged with the authority to consent to the administration of all psychotropic medications for youth in its custody. The DCFS Authorized Agent is then designated by DCFS Guardianship Administrator to consent to psychotropic medications on behalf of DCFS.<sup>34</sup>The DCFS Authorized Agent works in concert with the Centralized Psychotropic Medication Consent Program within the DCFS Office of the Guardian.<sup>35</sup> The Centralized Psychotropic Medication Program includes both a DCFS Psychiatric Consultant and a contracted medical review panel housed at the University of Illinois.

#### **INFORMED CONSENT PROCESS**

Once a health care provider determines it is necessary to administer a psychotropic medication for a child in DCFS custody, the caregiver is required to inform the health care provider that: (1) the child is in foster care, (2) consent of the DCFS Authorized Agent is required prior to administration of the medication (see Table 4 for descriptions), and (3) the psychotropic medications may only be administered pursuant to the Illinois Administrative Code.<sup>36</sup> The health care provider or DCFS caseworker will then contact the DCFS Authorized Agent. The DCFS Authorized Agent refers to the *Pharmacy and Therapeutic Manual*, which lists approved psychotropic medications for youth in foster care. The manual includes descriptions of the medications, acceptable ranges of dosages, contraindications, and time limits for requests to authorize prescriptions.<sup>37</sup> The manual also provides guidance as to whether consultation is required by the psychiatric consultant or medical review panel.

**Table 4. Key Stakeholders** 

Stakeholder	Role
DCFS Guardianship Administrator	Designated by DCFS to appoint and authorize the DCFS Authorized Agent to issue informed consent. <sup>38</sup>
DCFS Authorized Agent	Authorized to consent to psychotropic medications for youth in foster care. <sup>5</sup>
DCFS Psychiatric Consultant	Specializes in child and adolescent psychiatry. Contracted by DCFS.5
Medical Review Panel	Comprised of board-certified child and adolescent psychiatrists and registered nurses housed in the Psychopharmacology Department at the University of Illinois, Chicago College of Medicine. This is contracted by DCFS. <sup>5</sup>

Once the DCFS Authorized Agent selects the appropriate level of review, the psychiatric consultant or the medical review panel makes recommendations to approve or deny the request. The DCFS Authorized Agent then approves or denies the request.<sup>39</sup> The authorized agent must render his/her verbal approval or denial within 24 hours of receiving the request, and a written decision must be submitted within 48 hours.<sup>40</sup> An Authorized Agent's approval specifies both the medications and specific dosages; any alterations require a new consent to be obtained in the same manner. All authorizations include a specified date for expiration; none lasting more than 180 days.<sup>41</sup> The DCFS Guardianship Administrator must review the Authorized Agent's initial decision within 30 days, and then every 90 days thereafter.<sup>42</sup> The consent process for youth in DCFS custody placed in residential care mirrors that for youth in foster care.<sup>43</sup>

<sup>&</sup>lt;sup>34</sup> www.psych.uic.edu/csp/physicians/Medication%20Guidelines.pdf. IL ADC Title 89, ch. III, Subchapter b, Part 325.

<sup>35</sup> http://www.psych.uic.edu/csp/physicians/procedure.html

<sup>&</sup>lt;sup>36</sup> IL ADC Title 89, ch III. Subchapter b, Part 325.60(e)

<sup>&</sup>lt;sup>37</sup> Id. at 325.30(d)-(f)

<sup>&</sup>lt;sup>38</sup> www.psych.uic.edu/csp/physicians/Medication%20Guidelines.pdf. IL ADC Title 89, ch. III, Subchapter b, Part 325.

<sup>&</sup>lt;sup>39</sup> Id. at 325.40(e)

<sup>40</sup> Id. at 325.40(f)

<sup>41</sup> Id. at 325.40(c)

<sup>42</sup> Id. at 325.30(g)

 $<sup>^{43}</sup>$  IL ADC Title 89, ch III. Subchapter b, Part 325.50

#### **EXCEPTIONS**

Youth ages 12 and older may refuse medication; youth ages 11 and younger may refuse on a case-by-case basis.<sup>44</sup> The DCFS Authorized Agent assesses the basis for the child's objection, which may include requesting that the caseworker determine the basis of the objection.<sup>45</sup> Youth ages 18 and older who remain in DCFS custody have the same rights as adults to refuse psychotropic medications as set forth in the Mental Health and Developmental Disabilities Code.<sup>46</sup>

If it is determined by the health care provider that a child for whom DCFS is legally responsible poses a threat of imminent serious harm to the self or others, psychotropic medication may be administered without prior approval of an Authorized Agent.<sup>47</sup>

Health care providers may choose to opt out of the medical review panel and instead receive an independent individualized consultation with another health care provider, who will make the recommendation to the Authorized Agent.<sup>48</sup> The opportunity for health care providers to opt out of the medical review panel arose as a response to health care provider dissatisfaction with the panel.<sup>49</sup>

#### **MONITORING**

The medical review panel maintains a database that includes the following: information about the youth; the prescriber; the prescription, including type of medication, dosage, and diagnosis; and the verification of informed consent. .50

Youth under DCFS custody in residential care receive an on-site review. This review is conducted monthly by a residential facility medical director, or by his/her designee, during which all psychotropic medications are inventoried. <sup>51-52</sup> Pursuant to the Illinois Administrative Code § 325.50(d)(1), the review verifies that the facility follows proper storage, dispensing, and consent procedures. <sup>53</sup>Oversight is ensured through annual DCFS on-site inspections; the Guardianship Administrator's office and the psychiatric consultant review all emergency and routine consent forms. <sup>54</sup> DCFS trains residential staff every six months, in accordance with Illinois Administrative Code § 325. <sup>55</sup>

<sup>&</sup>lt;sup>44</sup> Data from the 2010 Multi-state study on psychotropic medication oversight in foster care study by L.K. Leslie (PI) at Tufts Medical Center.

<sup>&</sup>lt;sup>45</sup> Id.

<sup>&</sup>lt;sup>46</sup> IL ADC Title 89, ch III. Subchapter b, Part 325.70(d) referencing; 405 ILCS 5/2-107 and 2-107.1

<sup>&</sup>lt;sup>47</sup> This report lacks information on how long a psychotropic may be used under emergency circumstances without prior authorized agent approval. By contrast, for children for whom DCFS is legally responsible who are housed in a residential facility, emergency medication may not be used for more than 48 hours, excluding Saturdays, Sundays and holidays. IL ADC Title 89, ch. III, Subchapter b, Part 325.50(c).

<sup>&</sup>lt;sup>48</sup> Data from the 2010 Multi-state study on psychotropic medication oversight in foster care study by L.K. Leslie (PI) at Tufts Medical Center.

<sup>&</sup>lt;sup>49</sup> Id.

<sup>&</sup>lt;sup>50</sup> Data from the 2010 Multi-state study on psychotropic medication oversight in foster care study by L.K. Leslie (PI) at Tufts Medical Center.

<sup>51</sup> IL ADC Title 89, ch III. Subchapter b, Part 325.50(d)(1)

<sup>&</sup>lt;sup>52</sup> Id.

<sup>&</sup>lt;sup>53</sup> Id.

<sup>&</sup>lt;sup>54</sup> Id. At 325.50(d)(3)

<sup>&</sup>lt;sup>55</sup> Id. At 325.50(e)

# **TEXAS**

#### **OVERVIEW OF SYSTEM**

In Texas, the administration of consent for psychotropic medication to youth in foster care<sup>56</sup> is an inter-agency process involving the judiciary, the Department of Family and Protective Services (DFPS), and contracted health networks. The judge designates a "medical consenter" to review and authorize all medical care, including psychotropic medications.<sup>57</sup> The medical consenter is typically a DFPS case worker, but may also be a biological parent whose rights have not been terminated, the foster parent, or any other person determined to be able to consent to medical care that is in the best interest of the child.<sup>58</sup> The Superior HealthPlan Network, a contracted health network, administers the STAR Health Program in collaboration with Integrated Mental Health Services (IMHS). The STAR Health Program monitors the administration of psychotropic medications to youth in foster care and seeks consultation with IMHS in cases where prescribing patterns are of concern. The clinical staff (e.g., nurses and licensed behavioral health professionals) at IMHS are contracted to review medication treatment plans, including psychotropic medications, for youth in foster care.<sup>59</sup> DFPS also employs Area Office Nurses ("Nurses") to monitor and review a child welfare database including data on psychotropic medications.<sup>60</sup>

Table 5. Key Stakeholders

Stakeholder	Role
Medical Consenter	Designated by judicial system to review and authorize prescription of psychotropic medications for youth in custody of DFPS. Medical consenter is usually DFPS case worker, but may also be biological parent whose rights are not terminated, foster parent, or any other person determined to be able to consent in best interest of child.
Superior HealthPlan Network	Contracted health network that administers STAR Health Program in collaboration with Integrated Mental Health Services (IMHS).
STAR Health Program	Monitors the administration of psychotropic medications to youth in foster care.
Integrated Mental Health Services (IMHS)	Contracts clinical staff (e.g., nurses and licensed behavioral health professionals) to review medication treatment plans utilizing psychotropic medication for youth in foster care.
DFPS Area Office Nurses (Nurses)	Monitor and review the health and mental health, including psychotropic medication use, in a child welfare database.

<sup>&</sup>lt;sup>56</sup> Texas Family Code 266.004. Tex. Fam. Code 266.003 (4) "Foster child" means a child who is in the managing conservatorship of the department.

<sup>&</sup>lt;sup>57</sup> http://www.dfps.state.tx.us/Child\_Protection/medical/medical-consent.asp

<sup>&</sup>lt;sup>58</sup> Texas Family Code 266.004(1), 266.004(2)

<sup>&</sup>lt;sup>59</sup> http://www.dfps.state.tx.us/documents/about/pdf/2009-03-09\_STARHealth-PMUR-FAQ.pdf.

<sup>60</sup> Leslie, LK, Mackie, TI, Dawson, E, Bellonci, C, Schoonover, D, Rodday, AM, Hayek, M, and J Hyde. Multi-State Study on Psychotropic Medication Oversight in Foster Care. Clinical and Translational Sciences Institute, Tufts University Medical Center. Boston. MA: 2010

#### INFORMED CONSENT PROCESS

When a child enters foster care, a judge identifies and authorizes a Medical Consenter as well as a substitute in case the designated Medical Consenter becomes unavailable.<sup>61</sup> Typically, DFPS will petition the court to serve as Medical Consenter. If DFPS is appointed, they must submit the name of their designated medical consenter, typically the DFPS case worker, to the court within five days.<sup>62</sup> In cases where an individual (e.g., biological or foster parent), not DFPS, is considered for consenting, the judge must select a Medical Consenter who is able to attend all medical appointments and consent to all medical treatments.<sup>63</sup> To inform the judge's decision, the DFPS caseworker prepares and submits a Summary of Medical Care at each status, permanency, and placement hearing that can be used by the judge to determine the needs of the child and the appropriate medical consenter.

Once authorized by the judge, the Medical Consenter is responsible to attend all health care appointments, and administer consent for all medical care, including psychotropic medications. The Medical Consenter is obligated to report to the court at regularly scheduled hearings to review the medical treatment for the child in foster care.<sup>64</sup> To provide guidance for judges, an interagency collaboration created the *Psychotropic Medication Packet for Judges Presiding Over DFPS Conservatorship Cases* (Judge's Packet). The Judge's Packet intends to assist the judge in deciding an appropriate Medical Consenter and the medical treatment of the child. All Medical Consenters, whether DFPS employees or not, must complete mandatory training.<sup>65</sup>

#### **EXCEPTIONS**

DFPS is required to inform all youth in foster care who are 16 or 17 that they or their attorney may petition the court to authorize their consent to some or all of their medical care.<sup>66</sup> The court will determine whether the youth are capable of consenting to some or all of their medical care, including psychotropic medications, and authorize the youth to do so by court order.<sup>67</sup> The court retains the authority, in certain cases, to order medical treatment when youth, who are authorized to consent, refuse medical care, including psychotropic medications.<sup>68</sup>

In an emergency, psychotropic medications may be administered to youth in foster care without authorization by the Medical Consenter.<sup>69</sup> In such cases, the health care provider must report the use of psychotropic medication to the Medical Consenter no later than the second business day after the provision of emergency care.<sup>70</sup>

<sup>61</sup> DFPS Policy 6521.2: Responsibilities of Medical Consenters and Back Up Medical Consenters. http://www.dfps.state.tx.us/Child\_Protection/medical/medical-consent.asp

<sup>62</sup> Texas Family Code § 266.004(c)

<sup>&</sup>lt;sup>63</sup> Texas Family Code § 266.004(i). DFPS Policy 6521.2: Responsibilities of Medical Consenters and Back Up Medical Consenters. <a href="http://www.dfps.state.tx.us/Child Protection/medical/medical-consent.asp">http://www.dfps.state.tx.us/Child Protection/medical/medical-consent.asp</a>.

<sup>64</sup> http://www.dfps.state.tx.us/Child\_Protection/medical/medical-consent.asp

<sup>&</sup>lt;sup>65</sup> Id.

<sup>&</sup>lt;sup>66</sup> "Through the PAL (Preparation for Adult Living) program youth 16 and over receive training about their medication, administration, side effects, etc." DFPS Policy 6521.42 Informing Youth about Certain Rights. Leslie, LK, Mackie, TI, Dawson, E, Bellonci, C, Schoonover, D, Rodday, AM, Hayek, M, and J Hyde. Multi-State Study on Psychotropic Medication Oversight in Foster Care. Clinical and Translational Sciences Institute, Tufts University Medical Center. Boston, MA: 2010. Texas Family Code § 266.010 Consent to Medical Care by Foster Child at Least 16 Years of Age.

<sup>&</sup>lt;sup>67</sup> DFPS Policy 6521.42 Informing Youth about Certain Rights. Texas Family Code § 266.010.

To issue an order, the court must find by clear and convincing evidence that the medical care is in the best interest of the youth and that; (1) the youth lacks the capacity to make a decision regarding the medical care; (2) the failure to provide the medical care will result in observable and material impairment of growth, development or functioning of the youth; or (3) the youth is at risk of causing substantial bodily harm to him/herself or others. In such a situation, the attorney representing DFPS may file a motion requesting the court to order the specific medical treatment or change the authorization to consent to medical care to DFPS. The motion must include the child's reasons for refusing medical care and a statement signed by the physician stating why medical care is necessary.

<sup>&</sup>lt;sup>69</sup> Texas Family Code § 266.009(a)

<sup>70</sup> Texas Family Code§ 266.009(b)

#### **APPEAL**

Select stakeholders (i.e., DFPS, a GAL, the child's attorney, a biological parent whose rights have not been terminated, a foster parent and the Court Appointed Special Advocate) retain the right to petition the court to order medical care they believe is in the best interest of the child.<sup>71</sup> In considering such a petition, judges consult the Summary of Medical Care and the Judge's Packet, as described above, and conduct a hearing with relevant parties involved in the medical treatment of youth in foster care.

#### **MONITORING**

A routine and formal monitoring system is operated to review and to recommend alterations to the administration of psychotropic medications.<sup>72</sup> This system involves STAR Health, IMHS, and data reports or recommendations that are reported back to the court in the Summary of Medical Care. The STAR Health Program, in collaboration with IMHS, also maintains a database that draws from Medicaid billing data, the SACWIS child welfare database, Health Passport, and the STAR Health network.<sup>73</sup> IMHS provides routine review of psychotropic medications through data transfers from the State and through its ongoing service management to STAR Health members. Referrals for a review can be made by any case worker, judge, foster parent, Medical Consenter or any other concerned entity. The standard used in the review is the *Psychotropic Medication Utilization Parameters for Foster Children* (Parameters).<sup>74</sup> If the administration of psychotropic medications is inconsistent with the Parameters, then a further review and consultation with the provider is conducted. While STAR Health Program has no authority to approve or deny the use of psychotropic medications, the consultation is utilized to figure out, in a collaborative process, how best to bring the treatment into compliance with the Parameters. Any alterations or recommendations will be evaluated by a judge at the next regularly scheduled hearing when the Summary of Medical care is submitted to the court. When concerning prescribing practices are identified, the judge may issue a court order to alter the medical treatment, including administered psychotropic medications.<sup>75</sup>

In addition, DFPS has Nurses consult in each regional office who monitor and review psychotropic medications that are prescribed to youth in foster care.

<sup>71</sup> http://www.texascasa.org/

<sup>&</sup>lt;sup>72</sup> A medical consenter must report the prescription of psychotropic medications to the caseworker or supervisor by the following business day. Protective Services Action 06-073, March 21, 2006.

<sup>73</sup> http://www.dfps.state.tx.us/documents/about/pdf/2009-03-09 STARHealth-PMUR-FAQ.pdf.

<sup>&</sup>lt;sup>74</sup> STAR Health uses the *Psychotropic Medication Utilization Parameters for Foster Children* which identifies eight "red flags" indicating that a review of a child in foster care's medication treatment plan is appropriate. The eight parameters are whether the child; (1) Has received a thorough assessment including a diagnosis of a psychiatric condition, (2) Is not receiving five or more psychotropic medications at the same time, (3) Is not receiving multiple medications for the same condition(s) as described in the parameters, (4)Is not receiving polypharmacy for a condition without a trial on a single medication, (5) Is not receiving medication dosages exceeding manufacturers' recommendations (6) Is receiving appropriate medications if of a very young age (7) Is receiving medication consistent with the stated diagnosis; and (8) Ensuring that primary care physicians are consulting with a psychiatrist when treating conditions other than Attention Deficit Hyperactive Disorder (ADHD), uncomplicated Anxiety Disorders or uncomplicated Depression

<sup>&</sup>lt;sup>75</sup> Texas Family Code § 266.004(g)

# **Interview Guide**

This interview guide provides the general questions asked during the study. Actual interview guides were modified, as appropriate, for each stakeholder group.

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Interviewer:	Identifier:	Location:
Notetaker:	Date:	Stakeholder Group:
Interview Questions		
I. Introduction:		
as you know, we're working of process for consenting to the emotional and behavioral heal aged 0-18 years. We are inte	on a project for the e use of psychotrop lth care needs of chi erviewing a large nu	and We are researchers at Tufts Medical Center, and Office of the Child Advocate. Our project is to review the current oic medications, which are medications prescribed to address the ldren in foster care. By children, we mean children and adolescents mber of people who have experience with this process from many d how the current process is working. We appreciate your time in
twenty people and our final re therefore encourage you to be	eport will summariz e as candid as possib	questions will be kept confidential. We plan to interview at least e the general impressions without identifying anyone by name. We ble. We will be recording our interview as well as taking notes. The alyses for the project. Is recording this interview okay with you? (if

Our interview will be comprised of three main sections—your background, your specific experience with the current process in Massachusetts requiring judicial approval for antipsychotic medication use among children in foster care, and any suggestions you may have as to improvements to the process. We've planned for our interview today to last about an hour- is that still okay with you?

# II. Lens (Keep brief):

- A. What is your current role?
- B. When did you begin working in your current role?
- C. What roles have you held in working with children involved with the child welfare system?
  - Do you have any other experiences with children involved with the Department of Children and Families, formerly known as DSS?

# **III. Current System:**

This interview is specifically about the process of authorizing medications to manage the emotional and behavioral health care needs of children in foster care. As you know, Massachusetts Department of Children and Families (DCF) regulations call for DCF to request approval from the court before certain medications, specifically antipsychotics, can be given to children in foster care. The process for getting this approval from the court is called the Rogers process. The court will appoint a Guardian ad Litem (GAL) known as a Rogers GAL to investigate, report, and make recommendations concerning the use of certain medications to help the court render a decision. In the end, a Rogers hearing is held at which the child and the child's parents are represented by counsel. DCF counsel is present as well as the DCF caseworker and usually the Rogers GAL. The following questions will focus specifically on your experiences with the Rogers process.

A. Did you receive specific training on the *Rogers* process?

- If yes, what training did you receive and by whom was the training given?
- B. What is your role in the *Rogers* process?
  - How many Rogers cases have you worked on per month?
- C. Can you walk me through a recent *Rogers* case that is representative of your experience working with the *Rogers* process?
- D. Please describe the case from the time you first began working on a *Rogers* case until its resolution.
  - Is that, in fact, the very first time that you were involved with the process for this case? Who else did you work with during this process?
  - How were changes in medication, such as dosage and type, monitored? How were changes in medication dosage handled? What about adding medications? If yes, can you walk me through this process?
  - Have you ever participated in a Rogers process in which the request was denied?
  - If yes, ask them to walk you through the details of what happened and what the final resolution was.
  - How much of your time in total would you estimate it took for this representative case (describe in detail)?
- E. Based on your experiences overall, how do you feel that the *Rogers* process is working?
  - What do you think works well?
  - What do you think does not work well?
  - What recommendations, if any, do you have for improving the Rogers process?

# IV. Future System:

- A. People have raised concerns that children in foster care receive too many psychotropic medications. Others have suggested that children in foster care don't get appropriate psychotropic medications. In a perfect world, what would the system for providing psychotropic medication oversight to children in foster care look like to you? *Pause for an answer before proceeding to the following probes.* 
  - States are choosing a number of different mechanisms for determining who can authorize medications. Please refer to the attached card and I'll walk you through different mechanisms states have chosen. *Pass card.* Some states have the prescriber and foster parent provide substitute judgment for a child in foster care. Other states rely on the child welfare staff, such as the social worker, area office supervisor, or mental health experts who work in a specialized child welfare unit. In other states, the child welfare agencies rely on a panel of mental health experts, housed at a local university, while other states rely on court approval as we do through the *Rogers* process. In your vision for the ideal system, where would the decision-making authority for administering a psychotropic medication ultimately lie?
  - Would you include all medications or the antipsychotic medications, specifically? What about the situation where children are on multiple medications simultaneously?
  - What do you see as the role for your profession in this process?
  - What do you see as the role for the judiciary in this process?
  - What do you see as the role of the foster parents in this process?
  - What do you see as the role of the birth parents in this process?
  - What do you see as the role of older children in this process?
  - At what age is this appropriate?
  - What else besides age should be taken into account when seeking the input of an older child?
  - What other programmatic features would be necessary for this system to work?
  - How would you know that the system was working? What indicators would you look to?
  - What would the challenges be in adopting the system that you described in Massachusetts?
  - What would need to happen in order to overcome these challenges?

#### V. Conclusion:

A. Thank you very much for your time today and for sharing your personal experiences, insights, and recommendations. Before we conclude our meeting, is there anything else related to this topic that we haven't asked that you would like to address?

- B. Finally, are you aware of any diverging opinions in your field with regard to these issues?
  - Is there anyone else with whom you think we should speak particularly in more remote areas of the state such as the Cape or Western Massachusetts?
- C. As we move forward with this study we are interested in hearing your feedback on our findings for this study. To do this, we will hold focus groups involving *Rogers* process stakeholders, later this year, would you be interested in participating in one of these sessions?
- D. If you have any follow-up questions or would like to contact us to share some further thoughts, please call the Office of the Child Advocate at 617-979-8360 and mention that it is in connection with the Tufts Medical Center research project. They will be able to take a message and we can get back to you. Thank you again.

# **DCF Regulation**

Code of Massachusetts Regulations
Title 110: Department of Children and Families

Chapter 11.00: Medical Authorizations (Refs & Annos)

### 11.14: Antipsychotic Drugs

1) "Antipsychotic drugs" shall mean drugs which are used in treating psychoses. Antipsychotic drugs include the below listed drugs by whatever official name, common or usual name, chemical name, or brand name they may be designated.

All isomers, esters, ethers, salts of, or any combination of, drugs listed below are deemed to be antipsychotic drugs. Such antipsychotic drugs shall include, but shall not be limited to:

	Generic Name	Trade Name
1	Acetophenazine	Tindal
2	Butaperazine	Repoise
3	Carphenazine	Proketazine
4	Chlorpromazine	Thorazine
5	Chlorprothizene	Taractan
6	Fluphenazine	Prolixin
7	Haloperidol	Haldol
8	Loxapine	Loxitane
9	Mesoridazine	Serentil
10	Molindone	Moban
11	Perphenazine	Trilafon
12	Piperacetezine	Quide
13	Prochlorperazine	Compazine
14	Promazine	Sparine
15	Thioridazine	Mellaril
16	Thiothixene	Navane
17	Trifluoperazine	Stelazine
18	Triflupromazine	Vesprin

- 2) <u>No Consent by Department.</u> The Department shall not consent to the administration of antipsychotic medication for any individual, but shall in all cases seek parental consent for children in Department care, or prior judicial approval for children in Department custody and wards of the Department.
- 3) Consent by Parents for Children in Department Care.
  - (a) When any individual, organization, facility or medical provider seeks to medicate with antipsychotic drugs a child, who is in the care of the Department, Department staff shall not consent to such medication nor shall the Department seek prior judicial approval for administration of such medication. The decision of whether to consent to such medication shall remain with the parents.
  - (b) If the Department has reason to believe that the parents are guilty of medical neglect by their consent to medicate with antipsychotic drugs or by their refusal to consent to medicate with antipsychotic drugs, the Department shall seek custody of the child through a court proceeding which alleges medical neglect.

(c) The 110 CMR 11.14(3)(a) and (b) apply whether or not the child consents to the administration of antipsychotic medication.

# 4) <u>Judicial Approval for Wards and Children in Department Custody.</u>

- (a) When any individual, organization, facility, or medical provider seeks the Department's consent to medicate with antipsychotic drugs a child, who is a ward of the Department or who is in Department custody, the Department shall seek prior judicial approval for administration of such drugs even if the child's biological parents have consented to the medication. *See Rogers v. Commissioner of the Department of Mental Health*, 390 Mass. 489 (1983); M.G.L. c.210, § 6.
- (b) Where antipsychotic medications have been previously prescribed for a child who is a ward of the Department or who is in the custody of the Department, and that child is currently being treated with antipsychotic drugs without judicial authorization, the Department shall initiate the process for judicial review and application of substituted judgment. Pending judicial review the Department shall not discontinue the prescribed treatment with antipsychotic drugs, because interruption or discontinuance of the treatment might cause severe medical complications and might violate the individual's legal right to treatment.
- (c) Neither a ward of the Department who has attained 16 years of age nor a child in the custody of the Department who has attained 16 years of age and who has voluntarily admitted him/herself to a mental health facility, shall have the power to consent to the administration of anti-psychotic drugs. The Department shall seek prior judicial approval for medicating such a child with antipsychotic drugs, even if such child consents to its administration. *See*M.G.L. c.201, § 6.

# 5) <u>Guardianship for Individuals Over 18 Years of Age.</u>

- (a) The Department shall not consent to the administration of antipsychotic drugs to an individual over 18 years of age who is in the care or custody of the Department.
- (b) Any individual over 18 years of age who is in the care or custody of the Department, and who is competent to make medical decisions, may consent to the administration of his/her antipsychotic medication.
- (c) If the Department believes that an individual over 18 years of age in the care or custody of the Department is not competent to make medical decisions, and failing action by the individual's parents, the Department of Mental Health, or other third person, the Department will file incompetency proceedings under M.G.L. c. 201. If the individual is adjudicated competent, then only such individual may consent to the administration of antipsychotic drugs. If the individual is adjudicated incompetent then the judge will apply a substituted judgment standard to determine whether antipsychotic drugs ought to be administered, and will issue appropriate orders.

# 6) Emergency Treatment with Antipsychotic Drugs.

- (a) Antipsychotic drugs may be administered for treatment purposes without parental consent or prior judicial approval only in an emergency (even though no threat of violence exists) and only if there is no less intrusive alternative to antipsychotic drugs.
- (b) An emergency for purposes of administering antipsychotic drugs for treatment purposes is an unforeseen combination of circumstances or the resulting state that calls for immediate action. *See Roe* at 42. It includes a situation where doctors, in their professional judgment, determine that the medication is necessary to prevent the immediate, substantial, and irreversible deterioration of a serious mental illness. *See Rogers* at 511. The possibility that a mental condition might deteriorate into a chronic, irreversible condition at an uncertain but relatively distant date is not an emergency. *See Roe* at 55.

- (c) In situations that fall within the purview of 110 CMR 11.00, no consent by the Department or parents is necessary (since the medical provider may make such determination) and therefore the Department shall not give consent nor seek parental consent.
- (d) If a child is medicated with antipsychotic drugs in an emergency situation and the doctors determine that the antipsychotic drugs should continue, then the Department shall follow the procedures for obtaining consent as though no emergency existed. *See Rogers* at 512.

### 7) <u>Use of Antipsychotic Drugs for Restraint.</u>

- (a) Antipsychotic drugs shall not be administered as a restraint of any ward or child in the care or custody of the Department when such restraint is for disciplinary reasons or for administrative convenience.
- (b) Antipsychotic drugs may be used for restraint only in cases of emergency, and only if there is no less intrusive alternative to antipsychotic drugs. An emergency for purposes of administering antipsychotic drugs for restraint is the occurrence of, or serious threat of, extreme violence, personal injury, or attempted suicide. Such emergency cases shall only include situations where there is the occurrence or a substantial risk of serious self-destructive behavior, or the occurrence or a substantial risk of serious physical assault. A substantial risk includes only the serious, imminent threat of bodily harm, where there is present ability to effect such harm. Predictable crises are not within the definition of emergency. Antipsychotic drugs may be administered for restraint only in accordance with the procedures set forth in 104 CMR (Department of Mental Health).

# **Additional Resources**

#### **ARTICLES**

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#### **STATE TOOLS**

<u>Department of Mental Health Policy #83-50: Antipsychotic Medications (Rogers Decision)</u>: This memorandum outlines the major implications of the "Rogers Decision" which requires court approval for the use of antipsychotic medication in facilities and programs within the Department of Mental Health, which includes programs serving youth in foster care. (http://www.mass.gov/Eeohhs2/docs/dmh/policy/policy\_83\_50.pdf)

<u>Department of Children and Families Code of Massachusetts Regulations: Chapter 11.00. Medical Authorizations:</u> This regulation specifies who can authorize the administration of 'routine', 'emergency', and 'extraordinary' medical care for youth in custody of the Department of Children and Families. Section 11.14 of this regulation specifies the use of antipsychotic medications as 'extraordinary' medical care, thereby requiring judicial approval as set forth by the *Rogers* process. (http://www.mass.gov/Eeohhs2/docs/dmh/policy/policy\_83\_50.pdf)

<u>Massachusetts Probate and Family Court Standing Order 4-11: Administrative Process for Uncontested Rogers Reviews and Extensions:</u> This standing order outlines the administrative review process, used by the Probate and Family Court, for "extraordinary treatment," including antipsychotics, that is uniform across the state. The standing order only applies to adults (not youth) with uncontested *Rogers* reviews and extensions.

<u>Psychotropic Meds for Georgia Youth in Foster Care: Who Decides?</u>: This report, written by Karen Worthington, JD, and published by the Georgia Supreme Court Committee on Justice for Children in January of 2011, provides recommendations for improving the health and safety of Georgia youth in foster care. (http://w2.georgiacourts.org/cj4c/files/Psych\_meds\_paper%20(2).pdf)

Additional tools available in the Appendix to Leslie LK, Mackie TI, Dawson EH, Bellonci C, Schoonover DR, Rodday AM, Hayek M, Hyde J. <u>Multi-state study on psychotropic medication oversight</u>. September 2010. Study Report. Boston, MA. Tufts Medical Center.(under "Research Reports and Manuals:"http://160.109.101.132/icrhps/prodserv/default.asp)

# **WEBSITES**

<u>Foster Care Alumni Association</u> (FCAA): The FCAA's goal is to connect the alumni community and to transform policy and practice, ensuring opportunity for people in and from foster care. The vision of FCAA is to ensure a high quality of life for those in and from foster care through the collective voice of alumni. FCAA intends to erase the differences in

opportunities and outcomes that exist for people in and from foster care compared to those who have not experienced foster care.

Fostering Connections Resource Center: This website, supported by Child Trends, provides a wealth of child welfare information including state policies, CFSR data, PIP plans, and IV-E amounts. This is a gathering place of information, training, and tools related to furthering the implementation of the Fostering Connections law. Specifically, the Resource Center aims to connect implementers with the latest information and the best experts and advocates working on these issues. The Resource Center provides the following: nonpartisan data sources, individualized technical assistance, tracking of implementation activity, opportunities to communicate with experts and peers, and stakeholder networks.

<u>Mental Health Practices in Child Welfare Guidelines Toolkit</u>: This toolkit, which corresponds with the Jensen et al. paper listed in the <u>Articles</u> section, is a product of a collaborative effort by Casey Family Programs, the Annie E. Casey Foundation, and the Resource for Advancing Children's Health (REACH) Institute. This toolkit is designed to help administrators, supervisors, and case workers put into action the recently published consensus guidelines for mental health in child welfare (*Child Welfare* Vol. 88, No. 1, 2009). The toolkit offers valuable tips and resources for mental health screening and assessment, psychotherapy, psychopharmacology, parent support, and youth empowerment.

<u>National Foster Parent Association (NFPA):</u> The NFPA is a non-profit, volunteer organization established in 1972 as a result of the concerns of several independent groups that felt the country needed a national organization to meet the needs of foster families in the United States. NFPA has grown from an original group of 926 foster parents, 210 social workers and 59 other professionals to an organization that represents thousands of foster families nationwide through foster parent affiliates.

Office of the Child Advocate (OCA). The mission of the OCA is to improve the safety, health and well-being of Massachusetts children by promoting positive change in public policy and practice. The OCA represents the commitment of the Governor and the members of the Legislature to improve services provided by state agencies to children and families in Massachusetts. The OCA is an independent office that reports directly to the Governor.

#### **U.S. LEGISLATURE**

<u>Public Law 110-351: Fostering Connections to Success and Increasing Adoptions Act</u> (http://www.fosteringconnections.org/tools/assets/files/Public\_Law\_110-351.pdf)